A MULTIPLE METHOD ANALYSIS OF PEER HEALTH IN THE DIABETES ONLINE COMMUNITY

by

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ABSTRACT

Diabetes is a complex condition that can significantly affect quality of life and economic burden. New approaches to promoting diabetes knowledge and support to enhance diabetes management are necessary. Peer health is occurring within the diabetes online community (DOC), although very little is known about how it is being used to help manage diabetes. The purpose of this research was to better understand peer health within the nonmoderated, nontrained peer context of the DOC.

In this multiple method approach, a cross-sectional survey was posted to DOC social media sites to describe adult DOC users, indicators of their health status, and perceived credibility of DOC information. A baby boomer subset of participants were interviewed to understand why they participated in the DOC, how they anticipated continued DOC use as they aged, and how they determined credibility of DOC information. Transcripts were analyzed using content analysis. Apomediation Theory guided this research.

There were several significant findings. Individuals highly engaged with the DOC had better glycemic control. DOC users had high levels of diabetes self-care, health-related quality of life, and social capital. Baby boomers were using the DOC to increase their knowledge to improve self-care and for emotional

support. The DOC was used in adjunct to, not in place of, regular healthcare visits to fill gaps in tacit knowledge and support. Baby boomer participants valued the wisdom of experienced individuals, “diabetes elders.” Participants employed a process to find credible health information through the guidance of peers. Overall, DOC users found the DOC to be helpful with very little harm reported, suggesting DOC use is beneficial with low risk. Finally, DOC users found information from their healthcare providers to be more competent and trustworthy than information from the DOC, indicating DOC users still find their healthcare providers valuable.

The findings from this research are promising. DOC users engage in a reciprocal process of sharing diabetes related experiences, encouraging knowledge attainment and support. Peer health in a naturally occurring online environment has the capacity to augment the traditional healthcare model by providing health information and peer support conveniently and at a low cost.

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CHAPTER 1

INTRODUCTION

Statement of the Problem

Diabetes remains a complex, global disease, despite decades of advancements in knowledge and treatment. Long-term complications of diabetes can be costly and impact quality of life. Healthy People 2020 set a goal to reduce the prevalence and economic burden of diabetes and to improve the quality of life for those who have, or are at risk for having diabetes (US Department of Health & Human Services, 2010). In order to achieve this goal, new approaches in diabetes management are needed to decrease costs and improve the quality of life for those who have the disease.

While both patients and medical providers have responsibilities related to diabetes management, patients are necessarily responsible for the vast majority of tasks and decisions in the day-to-day management of diabetes. Supporting patients in self-management is critical because patients who are knowledgeable about managing their own diabetes have better glycemic control (Colleran, Starr, & Burge, 2003; McPherson, Smith, Powers, & Zuckerman, 2008). Further,

patients who are actively engaged with their health have better communication with their healthcare providers (Lorig et al., 1999), are more likely to follow recommended testing procedures and medical advice (Remmers et al., 2009), have improved health status (Lorig et al., 2001, 1999) and cost-savings (Lorig et al., 2001, 1999; Remmers et al., 2009). Therefore, healthcare providers should support patients in improving their knowledge about diabetes, including practical day-to-day diabetes management skills. One mechanism to promote improved self-management and knowledge about diabetes is through the use of resources on the Internet.

The Internet is increasingly used as a source for health information. According to the Pew Research Center Internet & American Life Project 79% of adults are using the Internet and, of those, 59% are looking for health information (Fox, 2011a). In fact, 23% of individuals with chronic conditions look online to find someone with similar health concerns (Fox, 2011b). The U.S. Department of Health (US Department of Health & Human Services, 2006) recognizes that e-health, (the intersection of medical informatics, public health, and commerce in context of the Internet) (Eysenbach, 2001) and Web 2.0 resources (health-related websites that allow for interaction and crowdsourcing content among users) can help patients manage their own health by providing tools for health promotion and disease self-management, access to healthcare records, decision support, support for behavior change, and access to online communities. Patients with access to e-health resources have tools to support engagement in their own healthcare. However, measuring meaningful e-health engagement can

be somewhat difficult to ascertain (Korda & Itani, 2013).

There has been a paradigm shift in which the patient role has elevated from a passive recipient to an active consumer of healthcare (McMullan, 2006). As active consumers, patients are seeking more information to assist them in making decisions about their health. This is particularly true for individuals with chronic conditions who need information that will allow them to be successful in disease management long-term.

Significance of the Problem

Peer health is gaining traction in chronic disease management as a way for patients to actively seek and engage in healthcare decisions. There are core functions of peer groups: to support day-to-day chronic disease management, encourage appropriate clinical care, and offer ongoing social and emotional support (Boothroyd & Fisher, 2010; Brownson & Heisler, 2009; Fisher et al., 2012). Heisler and colleagues (2010) suggest peer interactions between individuals with diabetes provide informational support, emotional support, and mutual reciprocity, which leads to improved diabetes attitudes, diabetes self-care and glycemic control. Peer health can also be used to support life transitions or times of uncertainty (Rasmussen, Dunning, & O'Connell, 2007). With the emergence of technology, peer health is increasingly assessed through the Internet. There are three types of peer health models, occurring both online and offline: 1) support group with a medical provider as the facilitator, 2) support group or one-on-one approach in which the facilitator is an individual who has

received formal training to be an advisor or coach to their peers, and 3) peer-led, nonfacilitated approach.

Due to the complex nature of diabetes, some people find peers helpful in providing social support in the self-management of their disease. A task force jointly convened by the American Association of Diabetes Educators and the American Diabetes Association (Funnell et al., 2012) recognized peer health as an important factor in diabetes management, although in the context of having a healthcare provider facilitate or monitor the peer health discussions. Further, peers who have received special training have been utilized to provide assistance in day-to-day chronic disease management, encourage appropriate clinical care, and offer ongoing social and emotional support (Brownson & Heisler, 2009; Fisher et al., 2012). In diabetes, trained peers have been used for formal face-to-face support/discussion groups (Fisher et al., 2012; Lorig, Ritter, Villa, & Armas, 2009), phone calls (Fisher et al., 2012; Heisler & Piette, 2005; Heisler et al., 2010), text support, and home visits (Fisher et al., 2012). Diabetes-related peer health has been associated with increased knowledge (Brown, Garcia, Kouzekanani, & Hanis, 2002; Lujan, Ostwald, & Ortiz, 2007) self-efficacy (Heisler & Piette, 2005; Lorig et al., 2009, 2010), patient activation (Lorig et al., 2009, 2010), communication with physicians, healthier eating habits (Lorig et al., 2009), and improved glycosylated hemoglobin (A1C) (Gilmer, Philis-Tsimikas, & Walker, 2005; Heisler et al., 2010; Liebman, Heffernan, & Sarvela, 2007; Lorig et al., 2010; Lujan et al., 2007; Markowitz & Laffel, 2012; Moore & Mengel, 2002; Thompson, Horton, & Flores, 2007; Two Feathers et al., 2005). Importantly,

reciprocal peer support has been found to be better than nurse care management with regard to A1C reduction (Heisler et al., 2010).

Medical providers have mixed feelings about patients who seek health information on the Internet (McMullan, 2006), including information hosted on diabetes online communities (DOC). Some healthcare providers have concerns about misinformation (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006; Moick & Terlutter, 2012), fearing a power imbalance (Murray, Pollack, White, & Lo, 2007; Snow, Humphrey, & Sandall, 2013) or challenge of authority (Murray et al., 2003) with regard to patients seeking online health information. Murray et al. (2003) found that 71% of patients who brought health information found on the Internet to a medical provider were seeking the opinion of the medical provider, not demanding unnecessary interventions such as tests, medications or referrals. Sidorov (2010) suggests online health information seeking, such as websites, blogs, and web-based messaging, which can overlap into social media, as additive, not substitutive to the advice of a medical provider. In addition, qualitative research conducted with individuals with Type 1 diabetes participating on an online discussion board found that participants were aware when comments posted by their peers might not pertain to them, and they “proceeded with caution” (Armstrong & Powell, 2009). Despite documented benefits (Heisler & Piette, 2005; Heisler et al., 2010; Lorig et al., 2009), there are currently no professional recommendations for individuals to use peer health to supplement their diabetes care. Further, the need for research specific to peer health was not recognized by the Robert Wood Johnson Foundation *Health e-Technologies*

Initiative: Building the Science of eHealth initiative (Emont & Emont, 2007), despite the increase in peer health resources.

Health information is not credible without trust in the message and source. Source credibility, the characteristics held that determine if the information is believable, is associated with perceptions of competence, trustworthiness, and goodwill/caring (McCroskey & Teven, 1999) and has been associated with emotional support in online communities. Putnam (2000) suggests trust is one of many positive factors that can come from social capital found in social networks, including online health communities. Research indicates general social media sites, such as Facebook, can facilitate social capital and trust (Ellison, Steinfield, & Lampe, 2007), although social capital is not commonly seen when connecting with strangers (Ellison, Steinfield, & Lampe, 2011), which may be more common within an online health community. Other research suggests online health community users with a preference for weak ties (bridging social capital), or diverse points of view based on firsthand knowledge of a health issues, are more likely to perceive information shared within the community as credible (Wright & Rains, 2014).

In online health communities, source credibility has been associated with relational communication and emotional support (Campbell & Wright, 2002). Trust in peers within an online health community may develop through the exchange of personal information and shared experiences. However, source credibility may be more difficult to ascertain in online environments due to reliance on text without the support of nonverbal cues and facial expressions

(Campbell & Wright, 2002; Wright, 2000), although emoticons may augment this. Source credibility is an important factor when determining credibility in online health information.

The prevalence of diabetes is increasing among baby boomers (King, Matheson, Chirina, Shankar, & Broman-Fulks, 2013; Martin, Freedman, Schoeni, & Andreski, 2009). With the rate of diabetes diagnosis increasing with age, and the progressive nature of diabetes, primary and secondary prevention approaches are key to affecting the health of the baby boomer generation. It is suggested that e-health can provide secondary prevention by providing information needed to improve diabetes knowledge and management (Renahy, Parizot, & Chauvin, 2008). While Internet use may differ among generations, there are few differences in online health information seeking behaviors (Fox, 2011a). Baby boomers are the first generation to transition into older adulthood with Internet skills. In fact, baby boomers make up 34% of the Internet population with 81% of younger boomers (born 1955-1964) and 76% of older boomers (born 1946-1954) going online with rapid adoption of social networking (Zickuhr, 2010). Because of this, the Internet will play a much greater role in the health of baby boomers than in previous generations. With the emergence of Internet technology, and the fast-paced adoption rate among baby boomers, peer health should be further explored as it relates to health indicators.

Theoretical Framework

Peer health has been a part of healthcare for several decades, including peer support groups and trained peer coaches providing one-on-one and group education. Peer health that bypasses the traditional hierarchical medical system through an apomediated environment is a relatively new phenomenon (Eysenbach, 2008a, 2008b). Apomediation is the process in which individuals are guided to credible and reliable information through the collaboration of peers who have produced opinions based on experience. Apomediation Theory proposes three ways in which to obtain trustworthy and credible health information: 1) intermediation, 2) disintermediation, and 3) apomediation. Intermediaries direct, disintermediaries inform without individualizing to the user, and apomediaries guide individuals to relevant and credible health information. Apomediation Theory will provide a framework for this study.

Purpose

The purpose of this exploratory multiple method study was to describe DOC adult users, indicators of their health status, and source credibility; and to characterize qualitative experiences of DOC users from a select population of users, baby boomers. Three data-driven papers were developed from this study. Paper 1 (Chapter 4) describes the characteristics of DOC users, and identifies relationships and interactions between those characteristics. The following health indicators were examined: health-related quality of life (HRQOL), social capital, diabetes self-care, and A1C. Paper 2 (Chapter 5) reports how baby boomers

(born between 1946-1964) describe their experience with the DOC, and inform the anticipation of further DOC use. Finally, Paper 3 (Chapter 6) examine how baby boomer DOC users perceive the credibility of information within the DOC and their healthcare provider team, and help and harm within the DOC.

Significance of the Study

The Agency for Heathcare Research and Quality (2014) has identified individuals with chronic conditions as a priority population to research. Chronic conditions, such as diabetes are costly. In fact, the estimated cost of diagnosed diabetes was $245 billion in 2012 (American Diabetes Association, 2013). In the current healthcare system, healthcare providers lack the time required to adequately manage diabetes and prevent complications (Østbye et al., 2005). Patients need to be responsible for diabetes self-care and are turning to e-health applications to support them in diabetes management activities. A review by Elbert et al. (2014) indicated that e-health interventions, such as the DOC, show promise in decreasing the burden of healthcare costs.

E-Health supports patient-centered care. A patient-centered healthcare system (Hawn, 2009; van der Eijk et al., 2013) is supported by putting patient preferences and values about how they want to receive healthcare front and center (Institute of Medicine Committee on Quality of Health Care in America, 2001), including the use of e-health interventions. Research studies on e-health applications are imperative in order to determine both positive and negative impacts on health. This research is

innovative because it examined users of a peer-led, naturally occurring, online community, the DOC.

Understanding DOC users and their use of the DOC will inform the healthcare system of potential solutions to costly diabetes care. This study provided data indicating several benefits of DOC usage. Models to support DOC use among individuals with diabetes should be further explored. Results of this study will be used to inform a future portfolio of research.

Specific Aims

Specific Aim 1

Describe the characteristics of DOC users, and identify the relationships and interactions between those characteristics.

Specific Aim 1.1

Characterize DOC users by demographics, health history, DOC intensity, DOC engagement, social capital, HRQOL, and diabetes self-care behaviors.

Specific Aim 1.2

Identify the relationship between the health history, DOC intensity, DOC engagement, social capital, HRQOL, and diabetes self-care behaviors.

Specific Aim 1.3

Examine interactions among demographics, health history, DOC intensity, DOC engagement, social capital, HRQOL, and diabetes self-care behaviors.

Specific Aim 2

Determine how baby boomers describe their experience with the DOC.

Specific Aim 2.1

Describe why baby boomer DOC users participate in the DOC.

Specific Aim 2.2

Describe how DOC users interact with their healthcare providers.

Specific Aim 2.3

Describe how baby boomers anticipate they would continue using the DOC as they aged.

Specific Aim 3

Examine how DOC users report credibility, help, and harm within the DOC.

Specific Aim 3.1

Describe the source credibility of the DOC.

Specific Aim 3.2

Examine differences in DOC source credibility, help, and harm among baby boomers and younger adult (born 1965-1980) counterparts.

Specific Aim 3.3

Determine if baby boomer DOC users view the DOC as an apomediated environment with regard to credibility.

Organization of Dissertation

This dissertation is organized into seven chapters: Chapter 2 provides an extensive literature review of e-health in healthcare. Chapter 3 describes the methods in which the research was conducted. Chapters 4-6 report the findings from this research. Chapter 4, “Engagement in the Diabetes Online Community Is Associated with Better Glycemic Control,” reports the results of Specific Aim 1. Chapter 5, “Diabetes Online Community Users Empowered by Reciprocal Peer Knowledge and Support,” reports the results of Specific Aim 2. Chapter 6, “Credibility of Information, Help, and Harm Within the Diabetes Online Community,” reports the results of Specific Aim 3. Finally, Chapter 7 concludes the manuscript with a summary of Chapters 4-6, discussion of research contributions and implications, and the direction for future research.

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CHAPTER 2

REVIEW OF LITERATURE

Introduction

Diabetes is a complex chronic condition that is increasing in prevalence. Online health information sources, including information generated by individuals with the same condition, may be helpful in knowledge attainment and support for those with diabetes. The diabetes online community (DOC) provides an avenue for individuals with diabetes to engage with one another to discuss diabetes related topics though a process called peer health. It is important to understand the current literature examining diabetes and health indicators, such as diabetes self-care, health-related quality of life, and social capital; and the DOC.

In addition to the rise in diabetes diagnosis, the population is also aging. Baby boomers are the first generation to age using the Internet and Web 2.0 applications during their younger years. With the aging population, it is important to understand baby boomers and their use of Web 2.0 applications to inform their diabetes management. Further, credibility of e-health sites is important in assuring information is accurate and relevant. This chapter reviews pertinent literature regarding diabetes, e-patients, e-health, Web 2.0 and the intersection of health, and the DOC.

Diabetes

In the United States, diabetes affects 25.8 million people and the numbers continue to rise. New adult cases of diabetes in the United States are projected to increase from 8 per 1000 in 2008 to about 15 per 1000 in 2050. The total diabetes prevalence, including both diagnosed and undiagnosed cases is projected to increase by 7% between 2010 and 2050 (Boyle, Thompson, Gregg, Barker, & Williamson, 2010). In addition, diabetes is the leading cause death and the leading cause of kidney failure, nontraumatic lower limb amputations, and new cases of blindness, and a major cause of heart disease and stroke (Centers for Disease Control Prevention, 2011).

Chronic conditions, such as diabetes, require ongoing attention and self-care behaviors. Engaging in diabetes self-care behaviors is critical in diabetes management and include healthy eating, being active, blood glucose monitoring, taking medications, problem solving, reducing risks, and healthy coping (Peeples, Tomky, Mulcahy, Peyrot, & Siminerio, 2007). It has been suggested that diabetes self-care behaviors are essential evidence-based constructs that must be included in diabetes research (Glasgow, Peeples, & Skovlund, 2008). Diabetes self-care strategies are derived from proper education and training. Education is a key component in diabetes self-care and has been proven to improve outcomes (Colleran, Starr, & Burge, 2003; McPherson, Smith, Powers, & Zuckerman, 2008; Norris, Lau, Smith, Schmid, & Engelgau, 2002; Renders, Valk, Griffin, Wagner, & Assendelft, 2001). According to the American Association of Diabetes Educators and the American Diabetes Association,

diabetes self-management education should be provided by one or more instructors, with at least one of the instructors being a healthcare provider. Other instructors may include community health workers or peers to encourage peer health (Funnell et al., 2012).

Health-related quality of life, a measurement of the overall well-being in individuals, should be an important objective in any health-related research (Kaplan, 2003). In diabetes, lower quality of life is related to less education, low income, older age, being female, insurance type (no insurance, Medicare or Medicaid), number of diabetes complications, number of comorbid conditions, and lower levels of physical activity (Glasgow, Ruggiero, Eakin, Dryfoos, & Chobanian, 1997). Over time health-related quality of life tends to remain constant or slightly decrease in females, while health-related quality of life increases in males (Naughton et al., 2014). In diabetes, lower health-related quality of life is related to major diabetes complications (Coffey et al., 2002; Glasgow et al., 1997; Laiteerapong et al., 2011), geriatric syndromes, hypoglycemia (Laiteerapong et al., 2011), and being female with greater body mass index (Naughton et al., 2014). Improving health status and perceived ability to control diabetes (Rubin & Peyrot, 1999), and improving knowledge through diabetes education has been found to increase health-related quality of life (Riaz, Rehman, Hakeem, & Shaheen, 2013). Health-related quality of life is not well understood among individuals engaged in online health communities for the purpose of peer health.

Social Capital

Social capital is the social connections—comprised of norms, networks, and trust—that allow individuals to work together as a community (Putnam, 1995). As individuals connect with others, the more they trust them, and are trusted by them. Social connectedness, in integral component of social capital, is a strong predictor of altruism (Putnam, 2001). There are two types of social capital, bonding social capital and bridging social capital. Bonding social capital is exclusive, including close family and friends, and promotes group cohesion. Bridging social capital is inclusive and is made up of a heterogeneous network with most connections representing weak ties. While bonding social capital has been linked to social support, bridging social capital allows for diffusion of information and diverse perspectives allowing access to new information and ideas (Putnam, 2000).

The term ‘social capital’ is typically used among sociologists and political scientists while ‘social support,’ a related concept, is often times used within the healthcare context (Burke, Kraut, & Marlow, 2011). Social capital has been extensively studied in online communities (Bode, 2008; Brandtzæg & Nov, 2011; Ellison, Lampe, Steinfield, & Vitak, 2010; Ellison, Steinfield, & Lampe, 2007, 2011; Johnston, Tanner, Lalla, & Kawalski, 2013; Shen & Cage, 2013; Steinfield, Ellison, & Lampe, 2008; Yoder & Stutzman, 2011) and warrants attention in online health community research.

A number of studies have found an association between social capital and health and mortality (Hamano et al., 2011; Kawachi, Kennedy, & Glass, 1999;

Kawachi, Kennedy, Lochner, & Prothrow-Stith, 1997; Lindström, 2004; Rose, 2000). Among a sample of adults with chronic heart disease and diabetes (*n*=300), multiple regression indicated that having a large network of social connections is associated with better self-management ($p<.001$), physical ($p<.001$) and mental well-being ($p<.001$), increased coping with their condition and decreased costs ($p<.01$) (Reeves et al., 2014). Dimensions of social capital, trust and solidarity ($B=-0.260$, $p<.01$), and empowerment and political action ($B=-0.188$, $p<.05$) were found to be significant predictors of A1C being < or ≥7% among a sample of middle-aged adults (*n*=60) (Farajzadegan, Jafari, Nazer, Keyvanara, & Zamani, 2013).

African American veterans with diabetes were found to have better glucose control when they lived in neighborhoods where people worked together to improve the community, a measure of social capital. There were no differences in glucose control when looking at other social capital measures such as participation in local groups or organizations, overall community rating, willingness to help neighbors with routine activities, feeling of belonging in the neighborhood, and trust of others in the community (Long, Field, Armstrong, Chang, & Metlay, 2010). Lack of social capital has been identified as a barrier in diabetes self-management (Henderson, Wilson, Roberts, Munt, & Crotty, 2014). Little is known about social capital as it relates to peer health.

The Internet

According to the Pew Research Center Internet & American Life Project 79% of adults are using the Internet, although use varies by generation: 95% of millennials (ages 18-34), 86% of Gen X (ages 35-46), 81% of younger baby boomers (ages 47-56), 76% of older baby boomers (ages 57-65), 58% of the silent generation (ages 66-74) and 30% of the G.I. generation (aged 75 and up) use the Internet (Fox, 2011a). The Internet became available in the mid to late 1990s, when the baby boomers were approximately 32-50 years old. During this time, many boomers were in their prime working years to which the Internet could have been a vital function of their job. Over time, there has been an increase of baby boomers using the Internet (Zickuhr, 2010). Gatto and Tak (2008) found that the majority of adults 59 or older use the Internet on a daily basis (55.17%) or five to six times per week (17.2%).

For older adults, perceived benefits of Internet use include connectedness, such as keeping in touch with people they already knew and making new friends; satisfaction, such as being fun, challenging, and/or stimulating; utility, such as paying bills or looking up travel information; and positive learning experiences (Gatto & Tak, 2008). Perceived barriers are frustration, such as difficulty keeping up with instructions and difficulty finding the information desired; functional limitations, such as neck pain and hands being stiff and numb (Gatto & Tak, 2008; Smith, 2014); mistrust, such as security breaches and viruses, and time, such as being addictive and time consuming (Gatto & Tak, 2008).

Internet access varies based on demographic and socioeconomic variables. In the 1990s males were more likely to be using the Internet. However, that gap seems to have since closed (Dholakia, 2006). Urban living is also positively associated with Internet use (Hale, Cotten, Drentea, & Goldner, 2010). With the increase in smartphone technology use, those in rural areas have increased access to the Internet (Kulkarni & Agrawal, 2008), although the increase between 2012 and 2013 did not appear to be significant (Duggan & Smith, 2013).

Education and income are strongly associated with Internet access and use (US Department of Health & Human Services, 2006). Specifically, those who were college educated or had a household income of $50,000 or more were more likely to use the Internet (Zickuhr & Smith, 2013). However, the gap within the digital divide appears to be closing with the uptake of Internet use among mobile users. Those who use their cell phone only for Internet use tend to be less educated and less affluent (Duggan & Smith, 2013).

The Internet as a Source for Health Information

An increasing number of websites are dedicated to health information. Eighty percent of Internet users are going online to look for health information, most often looking up symptoms and treatments (Fox, 2011a). Women are more likely to seek health information than men (Baker, Wagner, Singer, & Bundorf, 2003; Cotten & Gupta, 2004; Dholakia, 2006; Escoffery et al., 2005; Hesse et al., 2005; Karavidas, Lim, & Katsikas, 2005; Taha, Sharit, & Czaja, 2009; Warner &

Procaccino, 2007; Ybarra & Suman, 2008). Individuals with higher education and income levels are more likely to access health information online than offline (Diaz et al., 2002; Taha et al., 2009) while individuals living in rural areas who are using the Internet are less likely to access it for health information (Hale et al., 2010). Similar to other Internet users, 80% of young baby boomers and 83% of old baby boomers are accessing the Internet for health information (Fox, 2011a). Thirty-one percent of mobile phone users have used their phone to look up health information, with African Americans, Latinos, those aged 18-49, and those who with at least some college education more likely to do so (Fox & Duggan, 2013b).

Individuals have the opportunity to seek out different types of health information though online and offline platforms. Leung (2008) categorized four clusters of health information: 1) health improvement, 2) medical treatment, 3) family health, and 4) health issues that are difficult to talk about. Some individuals may find that accessing health information online is less embarrassing than offline sources. Further, Cotten and Gupta (2004) found that individuals who sought health information online, rather than offline, self-reported higher well-being and general happiness.

The quality of health information on the Internet varies (Purcell, Wilson, & Delamothe, 2002) and includes controversial topics and opinions. Medical providers have concerns about individuals seeking health information from the Internet (Broom, 2005; McMullan, 2006) before seeing a medical provider (Hesse et al., 2005). However, in a longitudinal telephone survey of participants aged 12

years or older (Mean age 48, *SD*=19; *n*=2007), more than 70% of online health information seekers were satisfied with the information they found online. Further, participants, especially older adults ($p<.05$) when compared to younger seekers, were more comfortable with information received from a healthcare provider after their online experience (Ybarra & Suman, 2008). Similarly, in a qualitative analysis, Kivits (2006) found that individuals (*n*=31) used health information they found on the Internet to complement, not oppose, the advice of their medical providers. Since the Internet can provide patients with a better understanding of health concerns, it has been seen to complement secondary prevention approaches (Renahy, Parizot, & Chauvin, 2008).

Lichtenfeld (2012) proposes that not all online health information, even websites and articles authored by healthcare providers or healthcare institutions/organizations, are reputable. The Health on the Net Foundation (2013) was formed as a solution to the confusion that can be caused by online health information overload. As a nonprofit, nongovernment organization, the Health on the Net Foundation promotes and guides reliable online health information by providing a quality label on websites it endorses. However, in one study individuals who observed a health information website with a Health on the Net quality label never clicked on the logo for more information (Eysenbach & Köhler, 2002), indicating that the lay public may not be aware of its purpose. There are no formal evaluation methods for lay individuals to determine if online health information is reputable; however, governmental agencies (US Food and Drug Administration, 2013), libraries (Medical Library Association, 2014; UC

Berkeley Library, 2014), and health centers (University of California San Francisco, 2014) have provided recommendations to help online users find credible information. Further, the Stanford Guidelines for Web Credibility were developed to help web designers improve website credibility based on a body of research (Standford Web Credibility Research, 2014).

There is conflicting evidence as to whether those who go online for health information are physically or mentally less healthy than those who do not go online. Baker et al. (2003) found that individuals were more likely to use the Internet for healthcare if they self-reported worse health status. In contrast, (Bessière, Pressman, Kiesler, & Kraut, 2010) found that using the Internet to communicate with family and friends is associated with decreased depression, supporting the value of social networking.

Seventy-two percent of adults living with one or more chronic diseases use the Internet (Fox & Duggan, 2013a). Individuals with at least one chronic disease were more likely to search for online health information than those without a chronic disease (Bundorf, Wagner, Singer, & Baker, 2006; Fox & Duggan, 2013a). Individuals with at least one of five chronic conditions (heart problems, cancer, diabetes, hypertension, or depression) reported that use of the Internet improved their understanding of their condition (48%), possible treatments (46%), affected the way they ate or exercised (32%), and improved their ability to manage their condition by themselves (27%) (Baker, Wagner, Singer, & Bundorf, 2003). Further, individuals with chronic conditions are going

online to learn about someone else's personal health experience (Fox & Duggan, 2013a).

Individuals with chronic conditions are more likely to turn to online support when they lack real world social support. An online survey conducted among individuals (n=40) engaged in an online support group for hearing loss indicated that lower levels of support from family and friends predicted higher levels of online support group use (b=-.79, p<.01) (Cummings, Sproull, & Kiesler, 2002). Similarly, individuals participating on a cancer-related list-serve (n=42) were more likely to read postings if offline support was low (p<.01) (Turner, Grube, & Meyers, 2001). Given the need for more support in managing health conditions, individuals are tapping into every health information source available to them (Fox & Duggan, 2013a). There are documented case reports of individuals faking an illness to join an online support group. This phenomenon has been coined Munchausen by Internet and described as a variant of factitious disorder (Feldman, 2000). Often these individuals are attempting to seek attention and sympathy, act out, and control others (Feldman, 2000; Pulman & Taylor, 2012). Individuals who make factitious claims about illness, although rare, could impact the credibility of the online health information.

Those without health insurance access the web for health information. Bundorf and colleagues (2006) found that individuals with chronic conditions who were uninsured were more likely than those who were privately insured to be frequent users of online health information. In "Dr. YouTube Will See You Now," Vogel (2011) describes how individuals are accessing the Internet for solutions to

their healthcare needs without seeing a medical provider due to costs for the uninsured, or wait times for those in countries who offer socialized medicine.

E-Patients

E-patients are individuals who go online to seek health information for themselves, or their family and friends (Ferguson & Frydman, 2004). E-patients have Internet access and can look up online health information for free 24 hours per day, 7 days per week, through a number of e-health applications. Given the access, cost, and type of information an e-patient can access and provide, e-patients should be considered "medical colleagues [that] could provide sustainable healthcare solutions" (Ferguson & Frydman, 2004, pp. 1148) and "heal healthcare" (Ferguson, 2007).

The e-patient movement is the "most technocultural medical revolution of the past century" (Ferguson & Frydman, 2004, pp.1149). However, pre-Internet medical paradigms can sometimes prevent healthcare providers from comprehending or seeing the value of what e-patients bring to healthcare (Ferguson & Frydman, 2004). Most healthcare providers don't realize the complexity and sociability of the information e-patients obtain from the Internet (Lester, Prady, Finegan, & Hoch, 2004). Lester's law states, "medical knowledge is a social process: The conversations that occur around artifactual data are always more important than the data themselves" (Ferguson, 2002). The information that is shared by patients provides more value than the actual data

related to the patient's health without regard to being in an offline or online format.

An online survey conducted on Sapient Health Network, an online service for those with chronic illness or serious illness, found that e-patients (*n*=191) preferred e-groups or online support groups, over physicians in 10 out of 12 aspects of care. These health aspects included most cost effective, best in-depth information on my condition, best help with emotional issues, most convenient, best for helping me find other medical resources, best practical knowledge of my condition, best help with issues of death and dying, most compassion and empathy, most likely to be there for me in the long run, and best technical knowledge of my condition. Physician care, specifically care by specialists, was preferred over online groups in two dimensions: 1) best help and advice on management after diagnosis, and 2) best help to diagnose my problem correctly (Ferguson & Kelly, 1999). This report, while germane to the topic of e-patients, was not published in a peer-reviewed journal and did not include statistics on age, gender, level of education, primary diagnosis, length of E-Group use, or other participant characteristics. The lack of peer-review and the 19% response rate could represent a biased sample, resulting in issues with generalizability.

E-Health

E-health is the intersection of medical informatics, public health and business, and references health services and information delivered or enhanced through the Internet and related technologies (Eysenbach, 2001). E-Health is

characterized by the networked global philosophy that using information and communication technology can improve health. The “E” in e-health stands for: electronic, efficiency, enhancing quality, evidence based, empowerment, encouragement, education, enabling, extending, ethics, and equity (Eysenbach, 2001). E-health sources include all programs that allow for computer mediated communication.

Neuhauser and Kreps (2003) propose that e-health has the capacity to effectively address components of health communication and behavior change with the following considerations: 1) health communication is more effective when it reaches individuals on an emotional level, 2) health communication is more effective when it relates to individual social or life contexts, 3) a combination of effective interpersonal communication and the reach of mass media communication is needed to change behaviors of populations, 4) tailored communication is more effective than generic messages; and 5) interactive communication is more effective than one-way communication. By being accessible on a 24-hour basis and within a format that provides an avenue for individuals to engage in a social way, e-health could enhance more intense patient engagement and participation, allow for widespread dissemination of information, provide customized information that is accessible to diverse audiences, include linkages to others for social support, and encompass information that relates more realistically to day-to-day health issues.

There are several general visions for e-health applications. First, e-health sources could enable patients to achieve self-efficacy and well-being by being

able to access medical information and support through social networks. Second, individuals in rural or isolated areas would have access to medical care without having to travel. Third, healthcare providers could manage their time more efficiently by receiving relevant and timely updates and share and discuss experiences through specialized social networks. Finally, teams of health professionals would work together and effectively through better coordination of care (Grasso & Paris, 2011).

Aging, Baby Boomers, and E-Health

The population is aging, putting strains on the current healthcare system. Baby boomers are particularly salient to the changes in the healthcare climate due to the fact that the oldest boomers reached 65 years of age in 2011 and are now accessing Medicare. In addition, the prevalence of diabetes is increasing among baby boomers (King, Matheson, Chirina, Shankar, & Broman-Fulks, 2013; Martin, Freedman, Schoeni, & Andreski, 2009). With the rate of diabetes diagnosis increasing with age, and the progressive nature of diabetes, primary and secondary prevention approaches are vital to affecting the health of the baby boomer generation. As previously stated, it is suggested that e-health can provide secondary prevention approaches (Renahy et al., 2008) by providing information needed to improve diabetes knowledge and management (Colleran et al., 2003; McPherson et al., 2008). Health outcomes for baby boomers related to online primary and secondary prevention approaches are unknown.

Although growing, Internet use remains low among older generations. In contrast, the majority of baby boomers are currently using the Internet (Fox, 2011a) and may continue to do so as they age. Baby boomers are the first generation to transition into older adulthood with Internet skills; because of this, the Internet and e-health will play a much greater role in the health of baby boomers than previous generations. An increased number of older adults using the Internet will increase access to pertinent e-health regarding aging specific conditions; conversely, the digital divide between those with low and high health literacy (Levy, Janke, & Langa, 2014) and/or no Internet access may increase.

Although younger adults and teenagers are more likely to become early adapters of social networking sites, use among baby boomers is rapidly increasing. In a nationally representative survey, the Pew Research Center found that between 2008 and 2010 the rate of social networking use rose from 20% to 50% in younger boomers and 9% to 43% in older boomers (Zickuhr, 2010). These findings are not isolated to general social networking sites; baby boomers' use of health-specific social networking sites is increasing as well. For example, in a recent study (Chung, 2013), over half of the participants in an analysis of health-related social networking sites were over the age of 50.

E-health resources, and social media in general, are still in their infancy stages and require attention from the research community. Baby boomers will be the first generation to have the ability to access social media before becoming Medicare eligible. Due to the novelty of social media, research has not been conducted to determine how social media will impact health as someone ages.

Given that baby boomers make up one third of the entire Internet population and traffic, and have shown overwhelming interest in social networking site use (Zickuhr, 2010), studying baby boomers will be the first step in determining how e-health might impact physical and mental health over time.

Computer Mediated Communication

Computer mediated communication is the process of information exchange that takes place within a collection of networks. Messages may be sent through synchronous or asynchronous means and can include several different forms of media, such as email, blogs, chat rooms, and audio or visual conferencing. Computer mediated communication allows people to interact, exchange, and perceive information (December, 1996). Nonverbal cues are not always apparent in textual communication seen with computer mediated communication, and therefore can be missed when compared to face-to-face communication (Wright, 2000). More recent technological advancements have included video exchange and the use of emoticons, impacting nonverbal cues. Computer mediated communication provides the foundation for web 2.0 applications.

Web 2.0 and the Intersection of Health

Web 2.0 is a term used to describe websites designed to facilitate interactivity and co-creation of content by website visitors (Walther et al., 2010). There are several examples of Web 2.0 applications. Wikis are documents that

are edited collaboratively by volunteers. YouTube is a video sharing network allowing for public comment by text or video. Blogs are individual or group opinion websites displayed in reverse chronological order that allow for interaction through comments. In more recent years, Web 2.0 resources have become widespread in users generating online health information.

Web 2.0 and healthcare converged when online applications to manage personal health records, such as Google Health, Microsoft HealthVault, and Dossia, were founded. There are several types of individuals who utilize Web 2.0 applications for health purposes. They include patients, health professionals, and researchers, each bringing their formal and informal expertise (Eysenbach, 2008b). While a hierarchy is seen in the traditional medical model, Barak and colleagues (2008) assert that formal credentials are neutralized when individuals go online.

There are various privacy and safety issues of concern as it relates to Web 2.0 applications for health. While Web 2.0 health applications allow for anonymity, (i.e., users who register with pseudonyms in place of their true identity), blogs tend to be very personal in nature and may include identifying information (Adams, 2010). Personal information found on Web 2.0 health applications can be used by marketers to sell medications or other health-related products (Lo & Parham, 2010). For example, if an individual made it public that they had an illness, various companies could try to market products that they claim would help with that illness. This direct to patient marketing is more likely to occur on websites that allow advertising. This may also affect an individual

seeking health or life insurance.

Individuals with chronic diseases are utilizing all types of Web 2.0 health applications to access and co-develop health information. Those with chronic conditions are more likely to sign up for alerts about health-related issues, learn about someone else's health experience, and post comments (Fox & Duggan, 2013a). Becoming informed through Web 2.0 health sources can promote autonomy and confidence to be activated in health decision making (Lo & Parham, 2010). With low cost and wide dissemination at a rapid pace, Web 2.0 can have a huge impact on public health (Vance, Howe, & Dellavalle, 2009).

Both companies and consumers benefit from the co-creation of online content in developing innovative products and services, and enhancing the relationship between the customer and company (Nambisan, 2009). In some instances, consumers are awarding prizes to innovators that are developing a product that meet their needs, rather than companies asking for consumer feedback. For example, since 2009, *DiabetesMine* (DiabetesMine, 2014), a popular diabetes blog, has challenged creative thinkers, including e-patients, to develop new products that will benefit those with diabetes. The annual DiabetesMine Innovation Project includes an online community vote to narrow down the finalists, while a judging panel decides who the winners are. Monetary awards are provided to the winners as start-up capital for product development. In this case, consumer driven crowdsourcing helps to determine what innovative products will get to market.

Not only are e-patients contributing to online healthcare content, they are being recognized for it. In 2011WEGO Health (2014), a social media company empowering the top 10% of online health social media contributors to connect with one another, provided awards to nominated online health activists who share their stories and experiences through Web 2.0 applications. In the same vein, Webcina (2014) hosted a contest in which contestants were asked to submit a story about how using social media has helped them as a patient or healthcare provider. Winners of these contests are provided with virtual badges that can display on their personal blog.

Web 2.0 is changing healthcare by allowing users to be more connected to information and each other. Below is a discussion of peer health and common types of Web 2.0 platforms.

Peer Health

Peer health allows for interactions among individuals with similar health conditions. Historically, peer health has been used in mental health as early as the 18th century, with an increase in traction in the late 1960s (Davidson et al., 1999) and continues to be prevalent today. The US Department of Veterans Affairs (2014) has recognized the importance of peer health in the management of mental health conditions, such as depression and posttraumatic stress disorder, by hiring peer specialists and peer support apprentices to support veterans. During the Web 1.0 era, in which interactivity was not a feature of the Internet, e-patients relied on health information provided by websites, and were

unable to connect or interact with other users. Through Web 2.0 features, e-patients can engage in online peer health, allowing e-patients to co-create and interact amid health-related content with other e-patients.

There has been a rise in peer health for chronic disease management. There are core functions of peer groups: to support day-to-day chronic disease management, encourage appropriate clinical care, and offer ongoing social and emotional support (Boothroyd & Fisher, 2010; Brownson & Heisler, 2009; Fisher et al., 2012). Heisler and colleagues (2010) suggest peer interactions between individuals with diabetes provide informational support, emotional support, and mutual reciprocity, which leads to improved diabetes attitudes, diabetes self-care and glycemic control. Peer health can also be used to support life transitions or times of uncertainty (Rasmussen, Dunning, & O'Connell, 2007).

Diabetes programs where peers have been trained to be “coaches” or “advisors” for the purpose of peer health, in addition to moderation by healthcare providers, has resulted in increased knowledge (Brown, Garcia, Kouzekanani, & Hanis, 2002; Lujan, Ostwald, & Ortiz, 2007), increased social support (Heisler et al., 2010) and improved A1C results (Brown et al., 2002; Gilmer, Philis-Tsimikas, & Walker, 2005; Heisler et al., 2010; Liebman, Heffernan, & Sarvela, 2007; Lorig et al., 2010; Lujan et al., 2007; Moore & Mengel, 2002; Thompson, Horton, & Flores, 2007; Two Feathers et al., 2005). However, peer education may not be helpful for all individuals with diabetes (Smith et al., 2011) and a secondary factor that unites peers, such as gender, culture, age, or shared experience (Heisler et al., 2010) may be necessary for optimal outcomes. It is unknown how

nonhealthcare provider moderated, nontrained peer interactions, as seen in the DOC, affect individuals and health outcomes.

Web 2.0 Applications

Online Encyclopedias

The most popular online encyclopedia with Web 2.0 features is Wikipedia, a web-based, free-content encyclopedia written collaboratively by volunteers. Wikipedia is one of the most popular websites in the world and has 413 million visitors every month. It was developed in 2001 by the Wikimedia Foundation Inc. (2014) and now hosts more that 31 million volunteer authored articles in 285 different languages. The English version of Wikipedia contains nearly 5 million articles. As with any encyclopedia, Wikipedia provides information related to medical conditions, and cites references users can access.

Online Video Sharing

Seventy-eight percent of all adults in the United States watch videos online (K. Purcell, 2013). Additionally, 25% of Internet users have watched an online video about health or medical issues (Fox, 2011c). Although the audience cannot co-create video content, they can rate videos (like, dislike) and provide textual commentary. YouTube (2014) is the most popular video sharing site. It was founded in 2005 and within a 7-month period, October 2009 to May 2010, video views per day went from over 1 billion to over 2 billion. Highly regarded health based professional organizations, such as the Center for Disease Control,

World Health Organization, and the American Diabetes Association, have YouTube video channels.

YouTube videos reflect both accurate facts and misinformation with regard to health. For example, although vaccinations are considered a safe and effective way to guard against infectious disease, there are many YouTube videos stating that vaccinations are dangerous. In a content analysis of YouTube videos, only 48% showed immunization in a positive light, 32% were negative about immunization, and 20% were ambiguous (Keelan, Pavri-Garcia, Tomlinson, & Wilson, 2007). YouTube videos about the Human Papillomavirus vaccine showed the Gardasil vaccination in a positive light nearly 75% of the time (Ache & Wallace, 2008). In a review of smoking cessation content on YouTube, very little information was based on strategies that have been proven effective (Richardson, Vettese, Sussman, Small, & Selby, 2011). YouTube can impact health decisions (Ache & Wallace, 2008) through its widespread use. Once a patient views a video on YouTube, they will receive suggestions about related videos or videos by the same author that may or may not provide accurate information. Therefore, Vance and associates (2009) suggest that medical providers should recommend specific YouTube videos their patients can access to obtain quality health information.

Blogs

A weblog, or blog for short, is a website that acts as a journal or diary in which entries are displayed in reverse chronological sequence (Herring et al.,

2005), with the majority being single-authored (Herring, Scheidt, Kouper, & Wright, 2007). Blogs may include photographs, videos, and links to other websites, but tend to be textually based (Herring et al., 2007; Papacharissi, 2007). Among Internet users, 12% are bloggers (Smith, 2008) and the popularity of blogs is increasing.

Blogs allow for others to respond to blog postings, creating a community. The formation and maintenance of a community is one of the five motivations for which people blog (Nardi, Schiano, Gumbrecht, & Swartz, 2004). The other four motivations are: 1) documenting one's life, 2) providing commentary and opinions, 3) expressing emotions, and 4) articulating ideas through writing.

The blogosphere is the interconnection between bloggers, where one blog will link or refer to the posting of another blog (Herring et al., 2005). Despite the vast number of blogs, very few blogs are actually linked to other blogs. Blogs that do link to another blog tend to be one-way ties to popular blogs (Herring et al., 2005). However, this statement can only be generalized to general blogs. It is unknown whether health-related blogs have a more blogosphere approach.

While blogs are becoming increasingly popular, bloggers have been found to experience blog burnout and stop blogging from time to time (Nardi et al., 2004). Blogging burnout is more likely to occur if the blogger isn't receiving positive feedback within their blog community (Chu, Young, Zamora, Kurup, & Macario, 2010). There is no research to indicate if blog burnout is associated with blogger personal health concerns.

Medical blogs are frequently hosted and read by the mainstream media (Kovic, Lulic, & Brumini, 2008) and have the potential to influence a large number of people. It is difficult to ascertain how many blogs are health-related as reliable searching would require bloggers to tag information within their post (Adams, 2010), and not all do. Of those medical blogs researched, 50-67% of the authors were working in the healthcare industry and 67-71% held a Master's or Doctorate degree (Kovic et al., 2008). Medical blogs are often accounts of the blogger's personal experience with a disease or condition or their experience with health professionals (Kovic et al., 2008; Miller & Pole, 2010)

Vlogs

Vlogs, also known as video web logs, video blogs, or video logs, are a form of expression captured on video and posted online to video sharing websites such as YouTube (Christian, 2009). Similar to a blogger writing a blog post, vloggers use video posts to express themselves. Vlogs create a community of individuals who share interests and have active interactions with each other (Warmbrodt, Sheng, & Hall, 2008). Vlog viewers are looking for a portrayal of something real, authentic, and sincere; acting and character portrayals are not generally accepted (Christian, 2009). Vlogs can be health-related. Typically when they are, it is from the personal perspective of the vlogger.

Discussion Boards

Internet discussion boards, also referred to as Internet forums and bulletin boards, are dedicated synchronous or asynchronous chat rooms where participants can focus the discussion on specific topics. Asllani, Ettkin, and Somasundar (2008) found that while blogs are more successful in communicating tacit knowledge for a general audience, discussion boards are superior in providing explicit knowledge intended for a specialized audience. Those who post on discussion boards seem to be intrinsically motivated, finding enjoyment in helping others, and receiving reciprocal feedback (Lee, Cheung, Lim, & Sia, 2006). Zrebiec (2005) found that among people with diabetes and their family members, 74% felt that participating in online discussions about diabetes helped them cope with the condition and 71% felt that participating in the online discussions helped them to feel more hopeful.

A descriptive analysis was conducted on the postings (*n*=1,179) of an online support group, housed within a computer-based bulletin board system, for individuals with disabilities (Braithwaite, Waldron, & Finn, 1999). Postings by unique profile names (*n*=42) during a 1-month period in 1995 were evaluated for social support. Given the retrospective nature of the postings, demographic data were limited to what participants offered on their own. Participants were distributed across the United States. The authors assumed an equal representation of males and females based on profile names and content in the postings. Participants mostly referenced physical disabilities. Two coders agreed there were 1,472 postings offering social support (offering caring, belonging,

esteem, or assistance). A pilot study using 10% of the postings took place to determine a taxonomy for which the categories of social support would be derived. Coding underwent a template type process, which appears to be similar to framework analysis. Categories from the final study include information support (31.3%), tangible assistance (2.7%), esteem support (18.6%), network support (7.1%), and emotional support (40%). Interrater reliability showed that categories were coded similarly 80% of the time (Scott's pi statistic was .76) and subcategories similarly 70% of the time with the exception of emotional support (55%), which was often times confused with information support. Unique support behaviors were provided in the context of humor, nonverbal cues, poetry, and signature lines. The results represented a small sampling of an online social networking site focused on disabilities, with an underrepresentation of psychological disabilities, and therefore cannot be generalized to other types of health concerns. There were 28 times more postings than individual profiles, suggesting that some individuals were posting multiple times. However, the number of posts by individuals was not reported, and the association of multiple posts by individuals with the offering or receipt of social support was not discussed.

A convenience sample (*n*=17) of adults with type 1 diabetes using an insulin pump for at least 6 months were invited to participate in a virtual clinic for a pilot study (Armstrong, Koteyko, & Powell, 2012). Participants were White, British ethnicity, and self-reported to be regular Internet users. Ages ranged from 22 to 70 years and the majority (*n*=11) were female. Participants were asked to

log in to the Virtual Clinic at least weekly; while there, participants could 1) access secure messaging between them and their healthcare provider, 2) find links to relevant health information, and 3) participate in an asynchronous, unmoderated discussion board. A thematic analysis of discussion board postings (34 discussion threads, 219 individual postings) revealed three recurring topics: 1) diabetes self-management, 2) learning about future treatments, and 3) coping with diabetes. Participants experienced social support that was reciprocated. Additionally, participants tested the limits of what could be discussed and corrected each other when misinformation was provided, such as not stopping insulin to lose weight. While the participants did correct someone who had brought up the notion of stopping insulin use in order to lose weight, the authors did not address whether or not participants corrected Participant 12, who brought up the fact that she was not changing her insulin pump cannulas as often as recommended. The degree to which participants will correct misinformation is unknown. The small sample and selection criteria limit generalizability.

Social Networking Sites

Social networking sites (SNS) have become increasing popular in recent years. The majority (74%) of Internet users engage in an SNS, a staggering 9-fold increase from 2005. This increase is nearly 11-fold when looking at individuals aged 50-64. There are no differences in SNS use with regard to gender, education level and household income (Pew Research Internet Project, 2014), which goes against the aforementioned relationship between higher

income and education levels with increased Internet access (US Department of Health & Human Services, 2006; Zickuhr & Smith, 2013). Additionally, African Americans (48%) and Hispanics (49%) are more likely than Whites (36%) to use a SNS on their mobile phones (Pew Research Internet Project, 2014). Disparities in Internet access exist based upon race. However, for those who do have Internet access, including access via mobile device, ethnicity does not impact use of social media (Chou, Hunt, Beckjord, Moser, & Hesse, 2009).

Online SNS are at the heart of health-related web 2.0 applications. SNS are web-based communities often grouped into smaller communities or groups based on common interests. These groups might include corporations, religious groups, or hobbies, and provide a means for Internet users to socialize, connect, and engage with other users. Special groups related to chronic conditions and other aspects of health have emerged within general SNS (i.e., Facebook, Eons), health-based websites with a community portal (WebMD, Yahoo!Health Expert Blogs) and condition focused SNS (patientslikeme.com, rareshare.org).

There are four main features to SNS: profiles, friends lists, tools for public communication, and stream-based updates (Boyd, 2010). Profiles about the individual members are central to SNS. Friends lists allow the public to identify connections between individuals. Tools for public communication are often supported by SNS and allow individual users to comment within a group or on an individual profile. Stream based updates allow individuals to broadcast content, such as text, website links, photos, or videos, on their profiles, allowing their friends within the SNS to view it. Friends may then comment on the stream

based updates, providing a running thread of content (Boyd, 2010). The amount of time spent updating status reports varies widely; only 15% of Facebook users update their status daily while 56% update less than once weekly (Hampton, Goulet, Raine, & Purcell, 2011), although these numbers are likely different today given the change in SNS use.

Individuals typically join an online community if they already have friends within that community, and if those friends are well connected to one another (Backstrom, Huttenlocher, Kleinberg, & Lan, 2006). A person also elects to belong to groups or communities due to shared interests. There are both risks and benefits to belonging to SNS groups. Some individuals experience social pressure to demonstrate their dedication to the value system upheld within the group which may or may not be advantageous. Belonging to a group can be risky if there is a lack of resources among members, or beneficial if members within the group have access to external information and resources (Valente, 2010).

SNS users are more trusting of people in general than non-Internet users (Hampton et al., 2011). Perhaps this is because there are general expectations within SNS of sociability, connection, geniality, and perhaps empathy and support (Parks, 2010). Personal connections have been found to be more important than professional sources when looking at emotional support for dealing with illness and quick remedies for everyday health issues (Fox, 2013) by neutralizing the status between individuals (Barak et al., 2008); therefore SNS connections may complement the current healthcare system.

SNS provide opportunities for communication between individuals, outside of their usual offline network, with whom they otherwise would not have opportunity to interact. These opportunities exist by breaking the barriers to initial interaction and facilitating the formation of common ground (Ellison et al., 2010). SNS can facilitate the interaction with a larger number of individuals (Donath, 2007; Donath & Boyd, 2004), thus increasing the number of available health information sources. These factors related to improving communication are particularly salient with regard to condition focused SNS.

There is evidence to suggest that SNS like Facebook can evoke a high positive valence and high arousal psychophysiological state, when compared to a relaxation or stress state (Mauri, Cipresso, Balgera, Villamira, & Riva, 2011). In other words, Facebook evokes high levels of excitement and engagement among users. There are also psychological benefits among members participating in SNS. In fact, based on a descriptive correlational telephone survey of 2,255 adults conducted by the Pew Research Center Hampton and associates (2011) concluded that Facebook use increases emotional support and companionship equal to that of being married or cohabitating with a partner.

Social Networking Sites and Social Capital

Social capital research as it relates to SNS has become popular in recent years. The intensity with which one uses Facebook is associated with bridging (Ellison et al., 2007; Johnston et al., 2013; Steinfield et al., 2008), bonding, and maintenance of social capital (Ellison et al., 2007; Johnston et al., 2013). When

comparing Facebook features (status updates, wall posts, chatting, and direct messaging), wall posts are associated with perceived bridging social capital among college students (Yoder & Stutzman, 2011). However, when controlling for age, gender, and education, Facebook use does not appear to increase offline social capital (Brandtzæg & Nov, 2011).

"Alloy social capital" a term coined by Sander (2005) after studying members of Meetup.com. Members of Meetup.com initially interact online, and then meet up in person. Sander argues that alloy social capital provides a stronger social capital than what online or face-to-face can do alone. Combining both online and face-to-face interactions increases social capital (Bode, 2008; Brandtzæg & Nov, 2011) but may come at the expense of bridging social capital due to the reduction of opportunities for new members (Shen & Cage, 2013).

Steinfield and colleagues (2008) argue that the more online friends an individual has, even weak ties, the more bridging social capital that is gained by having a heterogeneous network. On the other hand, having more friends has also been tied to social judgments being made on the profile owner (Donath & Boyd, 2004; Tong, Van Der Heide, Langwell, & Walther, 2008). For example, one might judge an individual for having too many friends listed on their profile. To date, there has been no research examining social capital in health-related SNS and how bridging or bonding capital relates to health indicators among individuals participating in online health communities.

Social Networking Sites and Health

Health-related SNS allow individuals to feel understood and obtain skills to cope with their chronic condition (Lo & Parham, 2010). Individuals who participate in online discussions about chronic conditions are empowered by the exchange of information, emotional support (Armstrong et al., 2012; Braithwaite et al., 1999; Gilbert, Dodson, Gill, & McKenzie, 2012; Oh & Lee, 2012; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009; van Uden-Kraan et al., 2008), amusement and humor (Braithwaite et al., 1999; van Uden-Kraan et al., 2008), recognition and understanding, shared experiences (Gilbert et al., 2012; van Uden-Kraan et al., 2008), and ability to help others (Chung, 2013; van Uden-Kraan et al., 2008). SNS use can afford users with a sense of empowerment, providing them the necessary skills to interact positively with their medical providers (Holbrey & Coulson, 2013; Maloney-Krichmar & Preece, 2005; Mo & Coulson, 2014; Oh & Lee, 2012). Empowerment is associated with other positive outcomes as well. Individuals who feel empowered feel better informed, feel confident in their relationship with their medical providers, treatment, and social environment, and have an improved acceptance of their disease, increased optimism and control, and enhanced self-esteem and well-being (van Uden-Kraan et al., 2008).

A qualitative analysis of Dutch participants (*n*=32) of a breast cancer, fibromyalgia, or arthritis support group to determine empowering process, disempowering process, and empowering outcomes. Potential participants were initially identified by the online support group webmasters. A semistructured

interview was conducted with each participant. Using two coders, an inductive analysis was used to determine themes and subthemes. The majority of participants were female (*n*=30), married or living with someone (*n*=26), and not employed or not able to work (*n*=25). Ages ranged from 21-75 years (mean 43 years, *SD* 12.3), disease duration was 0 to 19 years (mean 2 years), and online support group duration was 0 to 6 years (mean 1 year). The empowering process included the exchange of information, encountering emotional support, finding recognition and understanding, sharing experiences and helping others, and amusement. The disempowering process included being unsure about the quality of information, being confronted with negative sides of the disease, and being confronted with complainers. Empowering outcomes included being better informed, feeling confident in the relationship with their physician, confidence in dealing with the social environment, increased optimism and control over the future, enhanced self-esteem, and collective action (van Uden-Kraan et al., 2008). The study is limited by the small sample size and fact that participants were selected because of their high utilization of the online community and may not represent community at large, specifically lurkers, individuals who read postings but do not contribute material.

Rheingold (1993) assumed that online communities would be based on shared interests and goals, and not geographic location; this assumption has been realized. Twenty-three percent of all adult Internet users with chronic disease have accessed the Internet to find others who might have health concerns similar to them (Fox, 2011b). PatientsLikeMe (patientslikeme.com) is

an example of an SNS in which individuals who have similar heath concerns virtually meet to anonymously share treatment, symptom progression and outcome data, and knowledge management (Brownstein, Brownstein, Williams, Wicks, & Heywood, 2009). Those with rare disorders, such as progeria and chronic autoimmune hepatitis, can utilize SNS as well. Given that rare disorders have a lower incidence, it can be difficult to find medical providers with expert knowledge of the latest treatment options and support from others with the same condition. RareShare.com, an SNS designed specifically for rare conditions, breaks down those barriers. Another example of an SNS is Kneeboard, a social networking site for individuals with knee injuries. Members of Kneeboard recommend medical specialists and places to find knee braces for unusual conditions due to shared concerns, despite geographic differences (Maloney-Krichmar & Preece, 2005).

General SNS have been used for sharing of health information as well. When searched for the most prevalent noncommunicable diseases, Facebook was found to have 757 health-related groups, 75.6% of which are patient groups (Farmer, Holt, Cook, & Hearing, 2009). This number is likely to be much higher today.

Social isolation and depression is common among individuals with chronic conditions. Feelings of loneliness can occur due to lack of support and understanding, even among family members and social circles. Using an SNS can increase psychological well-being (Steinfield et al., 2008) and decrease feelings of alienation (Sparud-Lundin, Ranerup, & Berg, 2011). Since SNS can

improve communication and shared interest, it may be able to provide a different level of support than one can find offline. This support and reciprocity among SNS members make the need for external governance obsolete (Maloney-Krichmar & Preece, 2005). Lack of external governance is one of the features of Apomediation Theory (Eysenbach, 2008a, 2008b), allowing individuals to access information traditionally held by healthcare providers through the knowledge and experiences of peers.

Measures for online community intensity and engagement measures have varied among various disease states (Batenburg & Das, 2014; Cobb, Graham, Bock, Papandonatos, & Abrams, 2005; Petrovčič & Petrič, 2014; Poirier & Cobb, 2012; van Uden-Kraan et al., 2009). Poirier and Cobb (2012) found that members of the health intervention based website, Daily Challenge, were more likely to open intervention related emails, visit the website more often, and report completing the actions they were prompted to perform if they had social ties to other members on the website. Engagement effects have also been seen with an online smoking cessation programs (Cobb et al., 2005; Strecher et al., 2008). These studies suggest that there is a social influence to online intervention adherence.

Although a major factor of social networking is interaction with other members, some users are passive or inactive (Kumar, Novak, & Tomkins, 2010). Lurkers (Boyd, 2010), free-riders (experience benefits from the information sharing of others without sharing themselves) (Coleman, 1988), and participatory surveillance (the notion that information should be shared, not traded; sharing of

information encourages empowerment) (Albrechtslund, 2008) have all been described in the health-related SNS literature and share the same passive SNS user characteristics. Using the horizontal or mutual practice in which users view posts but do not initiate posts (Albrechtslund, 2008), lurkers, free-riders, and those engaged in participatory surveillance are not visible to other members (Boyd, 2010). Passive SNS users benefit from the participation of others, but do not reciprocate that benefit (Coleman, 1988). Benefits include having the same feelings of empowerment (Albrechtslund, 2008; van Uden-Kraan et al., 2009) as those who do post and feeling better informed and more confident in their relationship with their physicians. They report improved acceptance of the disease, feeling more confident about treatment, enhanced self-esteem, and increased optimism and control (van Uden-Kraan et al., 2009). Lurkers, free-riders, and those engaging in participatory surveillance gain personally through the sharing of their peers.

Dutch online support group lurkers with breast cancer, fibromyalgia, and arthritis were evaluated for their sense of empowerment (van Uden-Kraan et al., 2009). Participants were asked demographic variables, the frequency in which they visited the online support group, how long it lasted, the reasons for using the online support group, and their general satisfaction with the online support group. Instruments included the SF-12 to evaluate physical and mental well-being; a 29-item, 4-point scale to evaluate the empowering process, and 38-item 5-point scale to evaluate the empowering outcomes. Both empowerment scales were developed from a qualitative study by the same author. Of those who completed

the online questionnaire (*n*=528), 21% (*n*=109) self-identified themselves as lurkers by stating “no” when asked if they ever contributed to posting to an online patient support group. Lurkers were more likely to be older (mean age 47 years versus 43 years, *p* = .002), have a shorter disease duration (3.7 versus 5.4 years, *p* = .001), and lower mental well-being (SF-12 sub score 37.7 versus 40.5, *p* =.004). Active participants were more likely than lurkers to report visiting online social support groups for social reasons, to enjoy themselves, and accessed the site as part of their daily routine (*p*<.001). Lurkers and active posters scored similarly as it relates to being better informed, feeling more confident in their relationship with their healthcare providers, greater acceptance of their disease, feeling more confident about the treatment, improved self-esteem, and increased levels of optimism and control. Lurkers scored significantly lower than active posters related to exchanging information, finding recognition, and enhanced social well-being (*p*<.001). There was a small sampling of lurkers among the three disease oriented online support groups studied. Active users may be more likely to participate in a study than lurkers. Results cannot be generalizable to all members within the breast cancer, fibromyalgia, and arthritis online communities. This study did not identify characteristics of those who would be considered less active.

Swedish speaking women with type 1 diabetes who had given birth to a child in one of two hospitals during 2007-2009 were studied for their use of online support. After initial contact by phone, participants were emailed the online questionnaire in which demographic information and open ended questions were

solicited. Age distribution was fairly even. The majority of participants (*n*=105, 76% response rate) were high school (43%) or university (55.8%) graduates, working (56.2%) or on parental leave (34.3%), had diabetes for 10-19 years (40.4%) or 20 or more years (41.3%), and used multiple daily injections (71.4%). The majority of women accessed the Internet for information related to risks related to pregnancy and diabetes (73.9%), diabetes management during pregnancy (60.9%), and breastfeeding and diabetes (51.1%). Of those using social media sites to seek diabetes information (*n*=95), 50% self-reported being passive participants. Open questions were analyzed using a directed content analysis based upon a theory of social support with four components: emotional, instrumental, informational, and appraisal support (Sparud-Lundin et al., 2011). This study was descriptive in nature, and only investigated the type of diabetes information that was solicited from online sources by Swedish speaking women with type 1 diabetes who had recently given birth to a child. Support scales were not utilized. A confusing aspect of the study related to the author's report of the child's age at the time of the interview being as high as 5 years. If this study was conducted on women who delivered between 2007-2009, and the study was published in 2011, children could not be older than 4 years. The content analysis methodology provided very little information and was the weakest aspect of this study. The results were difficult to follow and text as it related to predetermined themes were not clear.

SNS can provide a sense of continuity and stability because it is available 24 hours a day, 7 days a week. If an individual wants to access information or

support in the middle of the night, there is access to do so. In addition, if an individual moves and requires another healthcare team, the SNS can remain a constant in their life. Further, members can access the SNS as often or as little as they like, some taking holidays from the SNS (Maloney-Krichmar & Preece, 2005). Overall, SNS improve access to health information and support that isn't available offline.

Diabetes Online Community

The DOC is a grassroots community developed by people affected by diabetes with the purpose of sharing diabetes knowledge and support based upon their experience living with diabetes. Although the DOC has been around for several years, to date there is no formal or academic definition of the DOC. DOC users, or peers, have diabetes themselves, or are family members or friends of someone who is affected by diabetes. It is difficult to ascertain how many people are using the DOC; however, it is global and appears to be growing. Notable are the registered users for TuDiabetes (35,000 members) and Type One Nation (23,000 members) and page views on Diabetes Daily (over 4 million from January – October 2014) (Diabetes Hands Foundation, 2014b; Juvenile Diabetes Research Foundation, 2014; G. Vieira, personal communication, November 3, 2014) at the writing of this manuscript.

There is a network of websites that make-up the DOC, including diabetes-specific and general social networking sites, discussion boards, blogs, and online videos. Through sharing and/or linking, information provided on one DOC site

may cross several social media platforms. Some DOC sites are moderated by employed or volunteer peers (i.e., TuDiabetes, Reality Check) and medical advice, inappropriate comments or participants are removed (Gilbert et al., 2012), although with large volumes of information, it may be difficult for a moderator to be aware of all issues. Other DOC sites are embedded within professional organizations, such as TypeOneNation supported by the Juvenile Diabetes Research Foundation (2014) or the online community built into the American Diabetes Association (2013) website. While there are no healthcare professional recommendations for DOC use and monitoring, several DOC sites are supported by healthcare providers who sit on their advisory boards or boards of directors (Diabetes Community Advocacy Foundation, 2014a; Diabetes Hands Foundation, 2014a).

The DOC is more than an online community and DOC users are increasingly engaged in activities other than asynchronous forums. Live chats where peers within the DOC facilitate programs that allow DOC users to participate in meaningful discussions on specific topics at a designated time are increasingly common and popular with DOC users. Examples include #DMSA and #ozDOC Tweetchats or Diabetes Social Media Advocacy Live podcast radio programs. DOC users are initiating campaigns to improve diabetes awareness, such as Blue Fridays (Diabetes Community Advocacy Foundation, 2014b), and to validate and encourage others with diabetes, such as the You Can Do This Project (2014). Walk with D (P4DC, 2013) was created by DOC users to address diabetes related stigma by increasing the visibility of real life with diabetes. DOC

users are also uniting in advocacy efforts to create change that improves the lives of individuals living with diabetes; one example is having DOC representation at the American Academy of Clinical Endocrinologists (2014) Conference on Glucose Monitoring. Finally, DOC users have come together to create products, sans FDA, to improve quality of life, such as NightScout, an open source “do it yourself” cloud-based continuous glucose monitoring project allowing users and other individuals to visualize fluctuations in blood sugar levels (The Nightscout Project, 2014). Another type of advocacy relates to informing healthcare providers and systems about the DOC. In her Ignite! Talk, DOC user Kim Vlasnik, founder of the popular You Can Do This Project (2014), poignantly spoke about the psychosocial impact of diabetes, and “how crucially important to my health it would be to hear two small words, “me too” (Standford Med X, 2014).

In a newsletter for the Juvenile Diabetes Research Foundation, Hernandez (2008) describes how being a member of a DOC provides a healing effect, “while we wait for a cure for diabetes, we can all support each other and raise diabetes awareness.” As a dlife.com correspondent, Hernandez (2009) shared 10 reasons why someone with diabetes should join a diabetes social network: 1) others with diabetes understand you, 2) exposure to other diabetes management practices, 3) gain knowledge about new research and treatment alternatives, 4) learn tips on how to navigate insurance companies and get them to cooperate, 5) get answers to many diabetes questions, 6) learn about side effects of drugs and devices, 7) learn things your healthcare provider may not know, 8) get support through rough times, 9) help others, and 10) make new

friends. With the DOC being fairly new, there is no research to substantiate these benefits.

Diabetes blogs are authored by individuals with varying types of diabetes and/or family members of those with diabetes. It is unknown how many diabetes blogs exist. Diabetes Social Media Advocacy, a program under the Diabetes Community Advocacy Foundation (2014c), has hosted a monthly blog carnival since February 2011. The blog carnival hosts a theme that diabetes bloggers are encouraged to blog about in order to obtain diverse perspectives on a similar topic. Topics have ranged from being lighthearted (i.e., creating a Disney character with diabetes) to more serious (i.e., life stages with diabetes, visiting with your doctor, or working with diabetes educators). Diabetes bloggers can link to other diabetes blogs, using a blogosphere approach. Further, blogs can be shared using a variety of Web 2.0 applications.

Oransky (2006) editorialized that diabetes bloggers can be used by pharmaceutical companies and device manufacturers to drive word of mouth marketing. Not all bloggers disclose if they are being financially compensated to write blogs about specific products, potentially impacting the market. Popular diabetes blogs, *DiabetesMine* and *Six Until Me* blog about the newest diabetes related products to come to the market based on the bloggers themselves being able to first try the products. Both blog authors report full disclosure of any financial compensation they receive related to the products they use in the blogs they might write about those products. There has been no research on diabetes blogs and full disclosure of financial compensation.

When searching on YouTube for a “diabetes vlog” (over 1400 videos), “diabetes blog” (over 2400 videos) or “diabetes diary” (over 200 videos), there is a wide range of information from individuals who have type 1, type 2, gestational diabetes and LADA (latent autoimmune diabetes of adulthood). Similar to blogs, these vlogs are meant to provide a personal account of someone’s experience with diabetes in video format. One example provides insight on how to manage the “diabetes police,” otherwise known as individuals who try to regulate the behavior of someone with diabetes (Lawson, 2008). Vlogs are an integral component of the DOC and are shared amongst several social media applications such as Twitter, Facebook, and diabetes specific SNS.

SNS range from general sites that are broadly used, such as Facebook and Twitter, to diabetes specific SNS, such as TuDiabetes and Diabetic Connect. Greene and colleagues (2011) found that among individuals using a diabetes group on Facebook, clinical information was shared, disease specific guidance and feedback were requested, and emotional support was provided, indicating a specific type of engagement within the DOC.

Discussion boards are highly valued among individuals in the DOC (Armstrong & Powell, 2009; Jennings, Powell, Armstrong, Sturt, & Dale, 2009) for their diabetes specific practical advice (Armstrong et al., 2012; Ravert, Hancock, & Ingersoll, 2004) emotional support (Armstrong et al., 2012; Gilbert et al., 2012; Oh & Lee, 2012; Ravert et al., 2004), shared experience (Cooper & Kar, 2014; Farrell, 2014; Gilbert et al., 2012; Ravert et al., 2004), and can be a source of confidence in diabetes management (Shaffer-Hudkins, Johnson, Melton, &

Wingert, 2014), inspiration, motivation, encouragement (Collins & Lewis, 2013), and empowerment (Oh & Lee, 2012). Discussion boards can be found in standalone websites or embedded within a SNS. Parallel to general health SNS, passive participants also access diabetes specific social websites to view posts, but not participate in them. Sparud-Lundin and colleagues (2011) found that 44% of participants with type 1 diabetes and a recent childbearing experience were passive participants while 45% were active participants.

Similar to other SNS, the safety of the DOC is a major concern. Bloggers, vloggers, and discussion board participants are free to share as much, or as little, personal information as they desire. SNS typically require the user to set up a profile. Most diabetes specific SNS provide the capability to secure individual profiles, protecting identifying information. Misinformation and improper medical advice can be a concern when seeking advice on a DOC. In the 'terms of use' section of many DOCs, it is recommended that members do not provide direct medical advice to other members. Advice can be generated based on a member's own experience and is not meant to be taken as prescriptive to other members. Further, members are encouraged to consult their own medical providers before making any changes to their treatment plans. Several studies have found that inaccurate health information is rare. In a Facebook diabetes group, clinically inaccurate information was infrequent, and was most often associated with the promotion of a specific product or service, including non-FDA approved products (Greene et al., 2011). Within a diabetes online virtual clinic (Armstrong et al., 2012) and an open-access DOC in Australia (Gilbert et al.,

2012), misinformation was also infrequent, and quickly corrected by other members in the discussion group. Further, in a nonmoderated online health forum for retired people, peer recommendations about type 2 diabetes fell within the best practice guidelines 91% of the time (Hoffman-Goetz, Donelle, & Thomson, 2009).

There are limitations to traditional healthcare delivery for individuals with diabetes that the DOC can help to dispel. These limitations are most often based upon lack of financial resources and limited access to medical providers. Financial limitations include insurance or lack thereof, office co-payments, medications, diabetes supplies, and travel to visit specialty providers if there isn't one locally available. Medical provider limitations can include lack of expertise in the diabetes specialty, lack of individualization, not being in-network on an insurance plan, and access due to location or scheduling issues. Limitations to health delivery are heightened in those living with diabetes in rural communities given the decrease of local resources. Individuals with longer travel times for healthcare are more likely than those with short travel times to use the Internet for health-related communication (Bundorf et al., 2006), suggesting the DOC would be beneficial to those in rural areas with limited access to specialty diabetes care. With the DOC being available 24/7, wherever you are, with individuals who also have diabetes accessing it, increased diabetes knowledge can be gained at a cheaper cost and with more convenience.

In a study of Koreans with diabetes (n=464), participants were engaged in one of five online communities (minimum of 5,000 members each) that provided

diabetes information and managed by individuals with diabetes themselves. Participants were more likely to be male (66.4%), college graduates (51.9%), be married (81%), have steady employment (74.4%), and feel that their health condition was not severe (55.8%). The participants' average age was 45.80 (*SD* 11.60) and they had been diagnosed with diabetes for 59.34 months (*SD* 31.36). Online community activity was addressed by asking questions about length of membership with a DOC, how many times per week the DOC is visited, and how many hours per week the person is on the DOC; Perceived Computer Mediated Social Support scale was modified from the Park's Social Support Scale and included 19 items. The Psychological Health Empowerment Scale was modified from the Diabetes Empowerment Scale and included 16 items, and the intention to actively communicate with the doctor was measured using 10 items modified from previous studies on the topic. Structural equation modeling was conducted. The more participants engaged in the DOC, the more social support they perceived from the other DOC members. The more someone felt social support from the DOC, the more they felt empowered. The more someone felt empowered, the more likely they were to intend to actively communicate with their doctor (Oh & Lee, 2012). While the revised scales have not undergone formal instrument testing, they did achieve Cronbach's alpha results between .70 - .92. Although the authors reported these results as they relate to Koreans with diabetes, nationality was not reported and cannot be assumed. The authors did not distinguish if the accessed DOC language was Korean or English, nor did they distinguish participants with type 1 and type 2 diabetes. The majority of this

sample was male. In the United States women are more likely to go online for health information. Assuming each DOC had only 5,000 members each (the minimum requirement), the response rate was very small at 1.85%. Given self-selection, it is difficult to generalize the findings of this study, though it potentially indicates the promising effects of DOC in some populations.

When seeking information from others with diabetes, members within a DOC and other condition focused SNS may be seeking peers with optimal heterophily (Rogers & Shoemaker, 1971). Optimal heterophily occurs when individuals have contact with others who have similar interests and a shared perspective with one distinct difference that one of the individuals in the group has experience in a certain area (Walther et al., 2010). For instance, someone who has been diagnosed with diabetes for several years might be able to share their experience with someone who has been recently diagnosed with diabetes. This peer health experience provides both a teaching and learning process for those involved. Also, the information is particularly apt and relevant as the person providing the information has already experienced what the information seeker is currently going through.

In education, “peer led team learning” occurs when the professional instructor is removed from the learning process, and students learn from one another (Pearce, 2010, p. 92). Peer led team learning is a pedagogic strategy in which students gain from teaching; to teach is to learn twice. Using “near peers” (teaching assistants, tutors, counselors) or “co-peers” (partnerships or workgroups) in peer led team learning increases cooperation and collaboration

because peers are less threatening than experts and they share a similar language (Pearce, 2010, p. 92; Whitman & Fife, 1988). The DOC exhibits a voluntary, peer led team learning-like process as individuals engage in meaningful discussions about diabetes.

Near peers or co-peers are teaching each other about diabetes in the DOC. Among physicians and interns, Schwenk and Whitman (1984) described experts (physicians) as being “unconsciously competent” (p. 44), resulting in difficulties with some of the nuances that need to be described and taught. On the other hand, near peers or co-peers (interns) are “consciously competent” (p. 44), and find it easier to teach because they have recently mastered the concept, and have to think through each step. Individuals with diabetes may be consciously competent in their ability to teach diabetes related activities such as carbohydrate counting or how to check a blood glucose level because they are recalling that knowledge continually.

Yamamoto and Matsumura (2009) found that word of mouth influence, in the blogosphere or offline, is based upon several “grassroots influentials” who have just a little bit more knowledge than a few “super influentials” who might be considered experts (p. 352). Individuals identified peer experts online as those who shared knowledge, especially hard to find information, on credible websites (Brown, Broderick, & Lee, 2007). The trust individuals may have in the efforts of grassroots influentials or peers plays a role in source credibility.

Aging and the Diabetes Online Community

The prevalence of diabetes is steadily rising among baby boomers (King et al., 2013; Martin et al., 2009) and the DOC can provide a mechanism to support this generation. For example, baby boomers are becoming Medicare eligible at the rate of 10,000 per day (National Council on Aging, 2014). Through the DOC, baby boomers can share information based on their experiences with Medicare and management of diabetes-related costs. Further, discussions surrounding senior fitness, co-morbidities, and other aging related health topics can be discussed within the DOC as well. With the baby boomer cohort being the first generation to age using Web 2.0 applications, it will be important to determine how baby boomers are currently using the DOC, and plan to use the DOC as they become older to inform diabetes management.

Source Credibility

Source credibility is an important construct within interpersonal communication (McCroskey, 1966) and relates to perceptions of competence, trustworthiness, and goodwill/caring (McCroskey & Teven, 1999). In online health communities, source credibility has been associated with relational communication and emotional support (Campbell & Wright, 2002). Trust in the information provided by peers within an online health community may develop through the exchange of personal information and shared experiences. However, source credibility may be more difficult to ascertain in online environments due to reliance on text without the support of nonverbal cues and facial expressions

(Campbell & Wright, 2002; Wright, 2000), although emoticons may augment this. Source credibility is an important factor when determining credibility in online health information.

Health information is so vast that it can be difficult to discern what is credible and reliable. In a 2006 national survey, only 25% of people seeking health information online checked the source and date of health information all or most of the time (Fox, 2006). Putting health information in the context of their own clinical situation might be difficult for some individuals (Lo & Parham, 2010), however not all (Armstrong & Powell, 2009). The guidance of peers may assist individuals better relate to health information.

Health information is not credible without trust in the message and source. There are conflicting reports regarding the association between trusting online health information and social capital. In the National Cancer Institute's 2007 Health Information National Trends Survey (*n*=7,674), social capital was not associated with online health information (Ye, 2010). However, the online health information was not embedded within an online community. Putnam (2000) suggested trust is one of many positive aspects that can come from social capital found in social networks, such as online health communities. Research indicates general social media sites, such as Facebook, can facilitate social capital and trust (Ellison et al., 2007), although social capital is not commonly seen when connecting with strangers (Ellison et al., 2011), which may be more common within an online health community. Other research suggests online health community users are more likely to perceive credibility within the community if

they show a preference for weak ties (bridging social capital), or diverse points of view based on firsthand knowledge (Wright & Rains, 2014) of a health issue. Source credibility is one of the domains identified in Apomediation Theory (Eysenbach, 2008a, 2008b).

Apomediation Theory

Eysenbach's (2008a, 2008b) Apomediation Theory will provide the framework for this study. Apomediation is the process in which individuals are guided to credible and reliable information through the collaboration of peers who have produced opinions based on experience. Apomediation theory proposes three ways in which to obtain trustworthy and credible health information: 1) intermediation, 2) disintermediation, and 3) apomediation. In the traditional medical model, healthcare professionals are the intermediaries or "experts" of credible and relevant health information. Intermediaries stand in between (*inter* is Latin for in between) the patient and the health information. Intermediation takes place when patients use their medical providers as their access to credible and relevant health information. Information on trusted websites approved by experts, such as the Center for Disease Control, World Health Organization, and other professional organizations can also be seen as intermediaries.

The Internet era has provided a hub for the dissemination of widespread health information. In disintermediation, the medical provider is bypassed and patients seek health information directly online. Without someone guiding them, patients must decipher what is credible and reliable on their own. Apomediaries

stand beside (*apo-* is Latin for away from), guiding patients within a shared application to credible and relevant information. Peers with similar health concerns, or apomediaries, are found in Web 2.0 applications such as wikis, blogs, and SNS, including DOCs (Eysenbach, 2008a, 2008b).

In order to tailor health information to individuals there is an intersection of personal health information or patient data and general health information or external evidence as noted in the left and right circles in Figure 2.1. In an

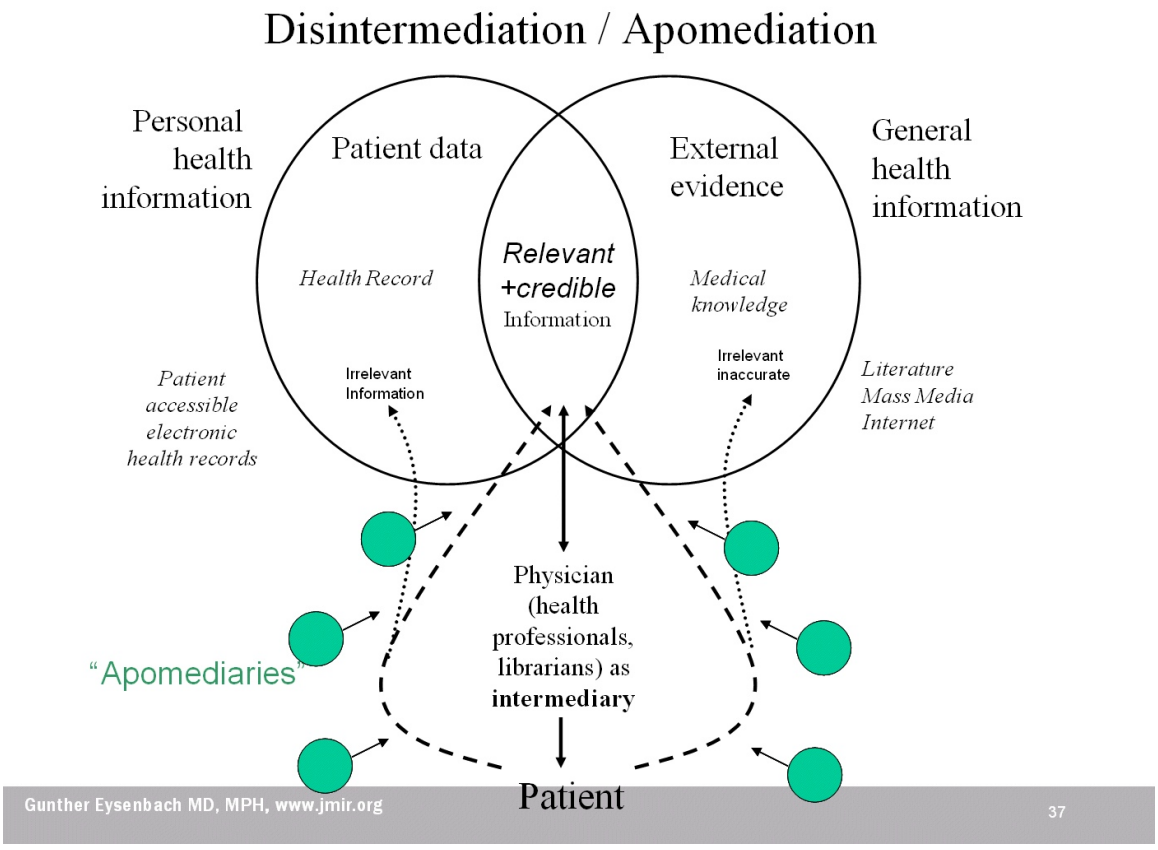

Figure 2.1. Disintermediation/Apomediation from the Patient Perspective. Reprinted from "Medicine 2.0: Social networking, collaboration, participation, apomediation, and openness," by G. Eysenbach, 2008, *Journal of Medical Internet Research, 10*(3), e22, http://www.jmir.org/2008/3/e22/. Copyright 2008 by the Journal of Medical Internet Research. Licensed under Creative Commons Attribution cc-by 2.0.

intermediated process, there is a bidirectional relationship between the medial provider and health information, but only a directive relationship between the medical provider and the patient as noted by the solid arrows. Patients are only receiving the health information their medical providers give them. In a disintermediated process, where the medical provider is removed from the model, patients can get lost with the overwhelming amount of information and might access irrelevant and untrustworthy information, as noted in the dotted arrows. According to the theory, apomediaries partly take over the role of intermediary by guiding patients, based on their own experiences, to relevant and accurate information, as noted by the dashed arrows (Eysenbach, 2008a, 2008b).

Individuals with diabetes can use the DOC to gather health information about their chronic conditions by learning of the treatments, side effects, complications, co-morbid conditions, technologies, special circumstances such as pregnancy or organ transplant, and insurance struggles their peers have experienced. Apomediaries will guide DOC users to decipher what health information is relevant and credible to them.

Individuals who prefer a disintermediated/apomediated environment over an intermediated environment differ in the way they view a hierarchical medical model, the nature in which they receive health information, as well as in age and acuity of illness. Eysenbach (2008a, 2008b) describes the differences between an intermediated environment and a disintermediated/apomediated environment through overarching issues (environment, power, dependence, nature of

information consumption, nature of interaction, information filtering, learning, cognitive elaboration, and user) and credibility issues (expertise, bias, source credibility, message credibility, credibility hubs, and credibility evaluations). See Table 2.1.

Eysenbach (2008a, 2008b) suggests that individuals may prefer an intermediated environment over a disintermediated or apomediated one depending on the nature of their medical condition as explained through the Dynamic Intermediation-Disintermediation-Apomediation model. See Figure 2.2. An individual may rely on medical providers, or intermediaries, for help initially navigating the medical system or a medical condition. However, once they have gained enough knowledge, self-efficacy, and autonomy, apomediaries take the place of intermediaries. Through a filtering process, individuals collaborate with experienced peers, apomediaries, who guide them towards credible and relevant information. Intermediaries are sought out again during acute illness or when apomediaries were not deemed useful (Eysenbach, 2008a, 2008b). One research report (Harkin & Huber, 2004) suggests that baby boomers use their “gut instinct” (p. 78) when evaluating the credibility of online health information, although this has not been substantiated in other studies. There is a lack of understanding about individuals who participate in peer health within the DOC. Research is needed to test Apomediation Theory to determine if the environment and credibility dynamics suggested in the model are apparent among individuals who engage in the DOC.

Table 2.1
Issues in an Apomediation vs. Intermediation Environment
Reprinted from "Medicine 2.0: Social networking, collaboration, participation, apomediation, and openness," by G. Eysenbach, 2008, *Journal of Medical Internet Research, 10*(3), e22, http://www.jmir.org/2008/3/e22/. Copyright 2008 by the Journal of Medical Internet Research.

Dimension	Intermediated Environment	Disintermediated/Apomediated Environment
Overarching Issues Environment	Managed	Autonomous
Power	Centralized; power held by intermediaries (experts, authorities)	Decentralized; empowerment of information seekers
Dependence	Information seekers dependent on intermediaries (physicians, parents); intermediaries are necessary	Information seekers are emancipated from intermediaries as apomediaries (peers, technology) provide guidance; apomediaries are optional
Nature of Information Consumption	Consumers tend to be passive receivers of information	Consumers are "prosumers" (i.e. co-producers of information)
Nature of Interaction	Traditional 1:1 interaction between intermediary and information seeker	Complex individual-and group-based interactions in a networked environment
Information Filtering	"Upstream" filtering with top-down quality assurance mechanisms	"Downstream" filtering with bottom-up quality assurance mechanisms
Learning	More formal; learning through consumption of information	More informal; learning through participation, application, and information production
Cognitive Elaboration	Lower cognitive elaboration required by information receivers	Higher elaboration required by information seekers; higher cognitive load unless assistance through intelligent tools

Table 2.1
Cont'd

Dimension	Intermediated Environment	Disintermediated/Apomediated Environment
User	More suitable for and /or desired by preadolescents, inexperienced or less information literate consumers, or patients with acute illness	More suitable for and/or desired by older adolescents and adults, experienced or information literate consumers, or patients with chronic conditions
Credibility Issues		
Expertise	Based on traditional credentials (i.e. seniority, professional degrees)	Based on first-hand experience or that of peers
Bias	May promote facts over opinion, but opportunity for intermediary to introduce bias	May bestow more credibility to opinions rather than facts
Source Credibility	Based on the believability of the source's authority; source credibility is more important than message credibility	Based on believability of apomediaries; message credibility and credibility of apomediaries are more important than source credibility
Message Credibility	Based on professional and precise language, comprehensiveness, use of citations, etc.	Based on understandable language, knowing or having experienced issues personally
Dimension	Intermediation Environment	Disintermediation/Apomediation Environment
Credibility Hubs	Static (experts)	Dynamic (opinion leaders)
Credibility Evaluations	Binary	Spectral

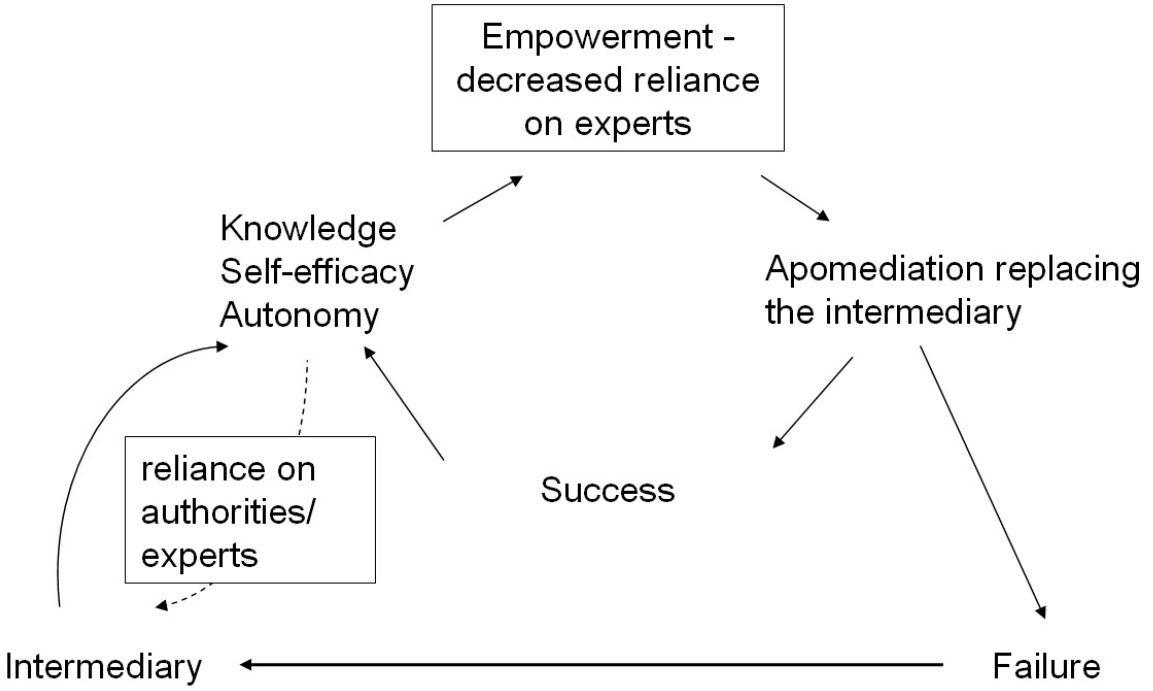

Figure 2.2. Dynamic Intermediation-Disintermediation-Apomediation Model. Reprinted from "Medicine 2.0: Social networking, collaboration, participation, apomediation, and openness," by G. Eysenbach, 2008, *Journal of Medical Internet Research, 10*(3), e22, http://www.jmir.org/2008/3/e22/. Copyright 2008 by the Journal of Medical Internet Research. Licensed under Creative Commons Attribution cc-by 2.0.

Summary

This literature review indicates Web 2.0 applications for health are vast and can provide emotional support, empowerment, self-esteem, increased acceptance of a disease, and more confidence in their relationships with healthcare providers. However, studies in this review cannot be generalizable due to language or location (Oh & Lee, 2012; Sparud-Lundin et al., 2011), being focused on those with type 1 diabetes only (Armstrong et al., 2012; Sparud-Lundin et al., 2011), or those with certain chronic conditions (Braithwaite et al., 1999; van Uden-Kraan et al., 2009; van Uden-Kraan et al., 2008). Research is

needed to better understand users of English-based DOC. Studies of the DOC did not measure social capital, source credibility, or report of diabetes self-care behaviors as they relate to DOC or SNS use. Health-based SNS have not been evaluated for social capital despite its association with health. It is important to examine how DOC users view bridging and bonding social capital within the DOC.

Members of the healthcare community express mixed feelings regarding patients using online health information. Measuring how DOC users view the source credibility of DOC and healthcare provider information will add to the current body of research. Prior studies did not evaluate diabetes self-care behaviors in those who use the DOC; measuring this will add another dimension to the current knowledge base. Finally, DOC intensity, as it relates to both frequency and emotional connection of DOC use, and DOC engagement are novel variables that have never been studied before in online health communities. Studying DOC intensity and engagement will inform how DOC use plays a role in health.

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CHAPTER 3

RESEARCH DESIGN AND METHODS

Introduction

The purpose of this chapter is to outline the methods of this study. Specific Aims 1-3 were completed using a multiple method approach to analyze peer health in the diabetes online community (DOC). In the quantitative arm of the study, DOC users were recruited to participate in an online survey. The purposes of the online survey were to describe the characteristics of DOC users, and identify the relationships and interactions between those characteristics (Specific Aim 1); and to examine how DOC users perceive credibility, help, and harm within the DOC (Specific Aim 3). Baby boomer respondents were subsequently recruited to be interviewed for the qualitative arm of the study. The purposes of the interviews were to understand how baby boomers describe their experience using the DOC (Specific Aim 2); and to comprehend how baby boomers perceive credibility within the DOC (Specific Aim 3).

Specific Aim 1

Describe the characteristics of DOC users, and identify the relationships and interactions between those characteristics.

Specific Aim 1.1

Characterize DOC users by demographics, health history, DOC intensity, DOC engagement, social capital, HRQOL, and diabetes self-care behaviors.

Specific Aim 1.2

Identify the relationship between the health history, DOC intensity, DOC engagement, social capital, health-related quality of life (HRQOL), and diabetes self-care behaviors.

Specific Aim 1.3

Examine interactions among demographics, health history, DOC intensity, DOC engagement, social capital, HRQOL, and diabetes self-care behaviors.

Specific Aim 1 Methodology

DOC users were examined extensively with regard to demographics and health indicators to address Specific Aim 1. The results of Specific Aim 1 are in Chapter 4. Chapter 4 is in the format of American Medical Association Manual 9th edition for submission to the Journal of Medical Information Research.

Design for Specific Aim 1

A prospective, exploratory, cross-sectional design was utilized to describe DOC users and explore relationships between DOC use and health characteristics.

Setting

The settings for this sample were DOC Internet sites. There were two diabetes-specific and two general DOC sites included in this study.

TuDiabetes

The first site was TuDiabetes, one of many DOCs on the Internet. It was selected for this study because it is hosted by a nonprofit organization, The Diabetes Hands Foundation. Nonprofit status allows TuDiabetes to be free of advertising. DOCs with advertising have been found to have lack of transparency, privacy issues (Orizio, Schulz, Gasparotti, Caimi, & Gelatti, 2010; Weitzman, Cole, Kaci, & Mandl, 2011) and unsubstantiated cures (Weitzman, Cole, et al., 2011).

Individuals can become TuDiabetes members by signing up through the webpage, Facebook, Twitter, Google, and Yahoo!. All members are screened by a program administrator before they can be accepted as a TuDiabetes member. There is an in-depth terms of service explaining privacy related matters including control over the profile page. Within a profile page, members have the option to personalize the aesthetics of their pages, friend other members, share the type of

diabetes they have and their most recent A1C levels, and the types of treatment/devices they utilize to manage diabetes. Like other SNS sites, TuDiabetes incorporates several Medicine 2.0 applications, including the sharing of blog posts, discussions, events, photos, and videos. TuDiabetes also crosses over into other SNS sites. For example, TuDiabetes has a Facebook page and Twitter handle. Additionally, there are applications that allow members to share their TuDiabetes posts on both Facebook and Twitter. Members can network with other members through over 22,000 forums (e.g., new to diabetes, type 1 diabetes, type 2 diabetes, latent autoimmune diabetes of adulthood, insulin pump), self-selecting nearly over 400 groups to belong to (i.e., “Oh!BABY!!” for individuals with diabetes who are or want to become pregnant, “Diabetics who run Marathons!,” “Diabetics with Depression,” “The Military and Diabetes”), and over 14,000 blog posts. Individuals do not have to be logged into their TuDiabetes profile to read blogs or discussions, see photos, or watch videos. However, they do have to be logged into their membership profile in order to generate content.

Many members of TuDiabetes have already been exposed to research as it relates to sharing data for public health, through TuAnalyze (Weitzman, Adida, Kelemen, & Mandl, 2011), and may see the benefits of DOC related research. The membership of TuDiabetes.org exceeds 35,000 members, with the majority having type 1 diabetes. Two thirds of members are women. The second largest age group among the membership is 45-65 years old.

Diabetic Connect

Diabetic Connect is a diabetes specific social media site and was the second site in this study. Along with social media sites for 24 other disease states, Diabetic Connect is owned and operated by Alliance Health. In addition to DOC user driven discussion boards, Diabetic Connect allows individuals to share and rate recipes and medications. Updated news stories regarding research and "Ask an Expert" activities are also available.

Individuals can register for Diabetic Connect through the website. Information can only be viewed if the Diabetic Connect user is logged into their account. Diabetic Connect users can add friends, follow the most popular discussions, and read blogs written by other Diabetic Connect members. Similar to TuDiabetes, Diabetic Connect hosts pages on both Facebook and Twitter in which there is DOC related activities. Dissimilar to TuDiabetes, Diabetic Connect is a for-profit organization and does have advertising for diabetes related products on their website.

Facebook

Facebook, the third site in this study, is a globally popular general social media site that provides individuals with opportunities to share and connect with others, including those with diabetes. Facebook users can make reciprocal connections with individuals the user knows (i.e., friends, family, or colleagues with "friend" status); however, through Facebook pages and groups, Facebook users can meet other people with common interests, such as diabetes. There are

more than 1000 diabetes-related pages and over 1000 diabetes-related groups. If a Facebook user “likes” a diabetes-related page or joins a diabetes-specific group, the page and/or group updates will be visible on the user’s Facebook news feed. Facebook pages can be filtered based on key words and/or who your “friends” like. Diabetes-related Facebook pages are typically developed for businesses, brands, or organizations. The purpose of Facebook pages is for organizations to share information and manage activity, such as private messages, in one location. Examples of diabetes-specific pages include the American Diabetes Association, TuDiabetes and Diabetic Connect.

Facebook groups are different from Facebook pages. Any Facebook user can develop a diabetes group and invite others to become members of the group. As acting manager, the Facebook user who originated the group can invite ”friends” to become administrators to share management of the group. Diabetes-specific groups can be filtered in the same way as Facebook pages with the addition of open or closed group status. Any Facebook user can join a group with open status. To become a member of a closed diabetes group, an existing member of the group must invite the Facebook user to the group, or a request must be sent by the Facebook user and approved by the group manager. Examples of diabetes-specific groups include “Diabetes Chit Chat” or “You Know When You’re A Type 1 Diabetic When…” Through diabetes-specific groups and pages individuals with diabetes can get to know one another and become “friends.” Once a friendship has established, users will be able to view each other’s personal Facebook activity on the home feed.

Twitter

Twitter, the fourth site, is another popular general social media site in which share messages called “tweets.” Tweets are limited to 140 characters. Twitter users do not have to reciprocate a relationship in order for one Twitter user to view another Twitter user’s tweets. Hashtags, which are searchable terms, are used in tweets to create community around discussions on certain topics, like diabetes. Popular hashtags for diabetes include #diabetes, #DSMA (Diabetes Social Media Advocacy), #DOC, #walkwithD, and #BGnow. When a twitter user searches a hashtag, they are able to view tweets by other Twitter users, regardless of “follow” status, who used that same hashtag in their tweet. In addition, there are diabetes-specific tweet chats such as the weekly #DSMA Tweetchat held in the United States and the #ozDOC Tweetchat held in Australia. While these Tweetchats may originate in one country, any Twitter user, regardless of country, can participate. On World Diabetes Day, November 14, 2014, a 24-hour global Tweetchat marathon was held which had nearly 19 million impressions (Symplur, 2014). Through searchable hashtags, Twitter users can connect and follow individuals they identify with or are interested in.

Sample

A convenience sample of DOC users was recruited from the above sites to participate in this study. To be included, participants had to have a diagnosis of diabetes, be 18 years of age or older, and have the ability to read English. Any participant who identified themselves as being a caregiver for someone with

diabetes (i.e., parent who has a child with diabetes), or less than 18 years old was omitted from the analysis.

Sample Size Calculation

Key survey questions concerned whether patients learn about diabetes through TuDiabetes in ways they could not from their healthcare provider alone. For purposes of sample size calculation, it was assumed that “yes” responses would be twice as prevalent as “no” responses, due to self-selection of participants who are actively participating in the DOC. This would be a proportion of .67 yes response and .33 of no responses. To be within a standard error of 3%, the critical value for a 95% confidence interval was 1.96 and resulted in the following formula:

$$.03 = 1.96*SE = 1.96*\sqrt{((p*(1-p))/n)}$$

Solving for n:

$$n = (p*(1-p))/(.03/1.96)^2 = (.667*(1-.667))/(.03/1.96)^2 = 948$$

The original sample size sought for this study was 948 by recruiting participants from TuDiabetes only. However, there were unforeseen issues with recruitment, detailed further in the recruitment section. Despite an expansion of the study to recruit participants from a second DOC site (Diabetic Connect), Facebook, and Twitter, 183 was the largest sample that could be attained. Fortunately the sample size was adequate to statistically determine significant

differences. Future studies should question very critically whether large samples can be recruited easily among online health communities.

Online Survey for Quantitative Analysis

A 129-question online survey (see Appendix A) was developed after completing a pilot study (see Appendix C). This survey was posted online for participants to complete.

Online Survey Sections and Instruments

The online survey was divided into seven sections: demographics, health history, Web 2.0 application use (including reasons to join a diabetes social network, DOC intensity, DOC engagement, and social capital), HRQOL, source credibility diabetes self-behaviors. Five validated instruments were used in this study and included the SF-12v2 (Ware, Kosinski, Turner-Bowker, & Gandek, 2002, 2007), an adapted version of the Facebook Intensity Scale (Ellison, Steinfield, & Lampe, 2007), the Internet Social Capital Scale (Williams, 2006), Source Credibility scale (McCroskey & Teven, 1999), and the self-care inventory revised (Weinger, Butler, Welch, & La Greca, 2005). This survey provided the data to address Specific Aims 1 and 3.

Demographics. Demographic data (11 items) included gender, marital status, education level, employment status, annual house hold income, age, ethnicity, race, country/state, living setting, and health insurance status.

Health history. Eight questions were dedicated to health history variables: type of diabetes, age when diagnosed with diabetes, current diabetes treatments, most recent A1C, type of medical practice and provider used for diabetes care, frequency of diabetes provider visits, and diabetes complications. Diabetes treatments were broken down into four categories: no treatment, oral agents only, one injected medication with or without oral agents, and intensive insulin management.

Health-related quality of life. The SF-12v2 was used to measure health status. The SF-12v2 is the second version of the SF-12, originally developed in 1994 to measure HRQOL through physical and mental component summary components. The SF-12 is a shortened version of the SF-36, while the SF-12v2 is a shortened version of the SF-36v2. The SF-12v2 and SF-36v2 offer significant improvements from the original versions. The SF-36v2 and SF-12v2 offer better instructions, simplified questions, improved layout, greater comparability with translations, and more clear response choices. Measuring eight health measurements (physical functioning, 2 items; role physical, 2 items; bodily pain, 1 item; general health, 1 item; vitality, 1 item; social functioning, 1 item; role emotional, 2 items; mental health, 2 items) within the physical and mental health domains (Ware et al., 2002, 2007). The SF-12v2 was adopted by the Agency for Healthcare Research and Quality and used in the Medical Expenditure Panel Study (Cheak-Zamora, Wyrwich, & McBride, 2009).

The SF-12v2 takes less than 5 minutes to complete and can encompass the general 4-week and acute 1-week recall period. Given the chronic status of

diabetes, a 4-week recall was utilized in this study. In this online survey, the SF-12v2 questions were presented similar to the paper form (Maruish & Turner-Bowker, 2009) to maintain the integrity of the tool. Norm based scoring (Mean = 50, *SD*=10) was used for this analysis (Ware et al., 2007). When tested in the general population in the United States, the Cronbach's alpha ranged between 0.73 and 0.87, with the mean physical component summary being 0.89 and mental component summary being 0.86 (Ware et al., 2007). Permission has been obtained through QualityMetric to use the SF-12v2 in this study.

Web 2.0 application use. Twenty-two individually scored items, developed by the investigator, were related to how the participants navigate social media applications, if the DOC has helped or harmed the participant, or anyone they knew; and if the participant's healthcare provider supports their DOC use.

Reasons to join a diabetes social network. Thirteen questions were developed from the Hernandez (2009) anecdotal dLife (diabetes life) article that assessed the importance of connections with others who have diabetes. It is important to note that Hernandez is the founder of the TuDiabetes, which served as one of the settings for the present study. Items were dichotomous, allowing a yes/no response.

DOC engagement. DOC engagement was measured by asking 5 dichotomous yes/no questions related to whether or not participants: shared clinical information, requested or provided clinical guidance or feedback, and received or provided emotional support. Greene and colleagues (2011), qualitatively analyzed the types of content posted by DOC users on Facebook;

the types of postings identified informed the development of the DOC engagement variable. A DOC engagement score was obtained by taking the mean score of the 5 variables and could range from 0 indicating low engagement to 5 indicating high engagement.

DOC Intensity Scale. The DOC Intensity Scale was adapted from the Facebook Intensity Scale (Ellison et al., 2007). The 8-item scale was designed to measure Facebook usage, active engagement, number of friends, time spent on Facebook, integration into daily activities, and emotional connection to Facebook. There are 5 responses for 6 of the 8 questions, ranging from 1=strongly disagree to 5=strongly agree. Two of the 8 questions are open-ended, seeking information about the number of Facebook friends one has and how many minutes per day are spent on Facebook. The survey takes less than 5 minutes to answer. In a study among college students, the scale reached Cronbach's alpha = 0.83. The word "Facebook" was be replaced with "DOC" in the revised scale for this study. Permission was obtained from the lead author of the Facebook Intensity Scale (Ellison et al., 2007) to use and adapt the scale for this study. The DOC Intensity Scale is calculated by taking the mean of all items in the scale, resulting in a continuous variable ranging from 0-5.

Internet Social Capital Scale. The Internet Social Capital Scale is designed to measure bonding and bridging social capital in both online and offline populations using a 5-point Likert scale to measure either broad Internet use or more specific Internet activities (Williams, 2006), such as DOC use. After reducing the original 36-item scale to a 20-item scale using factor analysis, the

online version was found to have a Coefficient alpha (Cronbach, 1951) of 0.900 and 0.889 for the offline version (Williams, 2006). The Internet Social Capital Scale comprises two subscales, a 10-item Bonding Subscale and a 10-item Bridging Subscale, and a five-point Likert response scale ranging from strongly agree to strongly disagree. The scale takes 5-10 minutes to complete.

The terms “offline” and “online,” which can be used interchangeably based on the study population, were replaced with “DOC” in this study. There were 3 questions from the Internet Social Capital Scale bonding subscale that do not pertain to the study population. The question, “If I needed an emergency loan of $500, I know someone online that I can turn to” was changed to “If I needed an emergency loan of diabetes supplies, I know someone on the DOC I can turn to.” The questions, “The people I interact with on the DOC would put their reputation on the line for me” and “The people I interact with on the DOC would be good job references for me” were omitted from the survey. Permission was obtained from Williams (2006) to use and adapt the Internet Social Capital Scale for this study. The adapted 7-item bonding social capital scale and 10-item bridging social capital scale each have possible scores of 0-5; higher scores indicate higher levels of social capital. In this study, the Internet social capital scale will measure DOC bonding and bridging social capital.

Source credibility. The revised source credibility scale was used to measure how participants viewed the credibility of the diabetes healthcare team and DOC peers. The source credibility scale was first developed in 1966 (McCroskey, 1966) and revised in 1999 (McCroskey & Teven, 1999). The

revised scale includes 18 items which measuring three factors: competence, trustworthiness, and goodwill/caring (McCroskey & Teven, 1999). The Source Credibility scale has been used to measure credibility of online discussions (Adi, 2007; Ng & Detenber, 2005; Stam, 2010; Tan, Swee, Lim, Detenber, & Alsagoff, 2007) and healthcare providers (Paulsel, McCroskey, & Richmond, 2006; Paulsel, Richmond, McCroskey, & Cayanus, 2005). The source credibility instrument uses a 7-point semantic differential scale, measuring and scoring competence (6 items), trustworthiness (6 items) and goodwill/caring (6 items) separately. The Cronbach's alpha scores range from .85 to .92 when looking at the dimensions separately, and .94 when scored as a single measure. The 18-item source credibility instrument can be completed in less than 5 minutes. This scale was used twice in this study, first, to measure how participants rated the source credibility of their diabetes healthcare team. The diabetes healthcare team included anyone who cared for the patient's diabetes. It was also used to measure how participants rated the source credibility of the DOC. Possible scores ranged from 0-42.

Diabetes self-care behaviors. The Self-Care Inventory Revised scale was used to measure diabetes self-care behaviors. The Self-Care Inventory was originally developed by La Greca and colleagues (1988) and later revised (Weinger et al., 2005) to measure diabetes self-care behaviors. The 15-item 5-point Likert scale Self-Care Inventory Revised measures diabetes self-care behaviors, accommodating for the natural variation in treatment plans for patients with type 1 or type 2 diabetes, and duration since diagnosis. Diabetes self-care

behaviors include checking blood sugar, taking medications, diet, exercise, treatment of hypoglycemia, going in for clinic appointments, and wearing medic alert identification. Each item on the Self-Care Inventory Revised is converted to a score between 0-100, a higher score indicating more self-care. The Cronbach's alpha for the Self-Care Inventory Revised in a study including 3 datasets was 0.85 (Weinger et al., 2005). The Self-Care Inventory Revised takes less than 5 minutes to complete.

Recruitment

DOC users were recruited to participate in the study in two waves. During the first wave only TuDiabetes members were recruited. TuDiabetes required all research conducted on their website be initiated through a program administrator. Permission to recruit from this site was sought and approved. Once approval was established, the study was advertised in two ways. First, a synopsis of the study, with a link to the survey, was posted on the “Diabetes trials, studies, and surveys” forum from the principal investigator’s personal TuDiabetes profile page (see Figure 3.1). Second, understanding that opinion leaders were critical for the implementation of interventions within a community (Valente, 2010), several community leaders were asked to share the research recruitment post to heighten awareness of the study. The viral nature of social media provided a medium for snowball sampling. Online survey participants were made aware that a $2 donation would be given to the Diabetes Hands Foundation for every survey conducted up to a maximum of $1000.

DOC and Health Outcomes Research

Posted by Michelle on August 25, 2012 at 2:31pm in Diabetes trials, studies and surveys View Discussions

Hello,

My name is Michelle Litchman. I am a doctoral student at the University of Utah College of Nursing. For my dissertation research I am examining online peer-to-peer health among individuals with diabetes. I am interested in knowing the relationship between the intensity to which someone is involved with TuDiabetes and their health. Currently, there is very little research about the Diabetes Online Community and peer-to-peer health.

I will be gathering data through a confidential survey that can be accessed online. The survey takes about 30 minutes to complete. Please link to the survey here. I will donate $2, up to $1000 maximum, to the Diabetes Hands Foundation for every survey that is completed.

Once the data has been analyzed, I will follow-up with the TuDiabetes community to share my findings. Thank you in advance for your participation.

Best Regards,

Michelle Litchman, MS, FNP-BC
University of Utah PhD Student

Figure 3.1. Research Recruitment Post

In the early stages of recruitment, some negative comments about the study and the principal investigator were posted in the comments section of the research recruitment post. These comments may or may not have affected a subsequent slowing in recruitment. To promote recruitment, the TuDiabetes administrative team made a comment on the post about the importance of this research. In addition, TuDiabetes included an advertisement in their online newsletter 4 weeks after the recruitment post originated. After 3 months a second wave of recruitment was initiated. A second diabetes specific social media site (Diabetic Connect) was contacted and authorized recruitment of their members for this research. The principal investigator became a member of Diabetic Connect and created a recruitment post with a synopsis of the study with the survey link. This post was identical to that written for TuDiabetes. Facebook and Twitter were used to share the recruitment post on a weekly basis for 3 weeks. The recruitment post from TuDiabetes was used due to the fact that TuDiabetes

postings can be viewed without regard to membership, which is not possible through Diabetic Connect. While potential participants were only directly recruited by the principal investigator from TuDiabetes, Diabetic Connect, Facebook and Twitter, the viral nature of sharing information across several social media platforms could have occurred, resulting in recruitment of participants from other DOC sites.

Informed Consent

Due to the nature of this study, this study was exempted by the University of Utah Institutional Review Board. Online informed consent is very similar to face-to-face informed consent, with the exception of eye strain from viewing the monitor and the inability to ask questions of the investigator during consent (Varnhagen et al., 2005). Participants were notified of the following elements: a) the study involved research, b) description of research procedures, c) voluntariness of participation, d) right to withdraw at any time without penalty, e) handling of data (anonymity, confidentiality), f) contact information for the researcher, and g) contact information for concerns about the project. Online survey participants were required to check a box stating they understood and agreed to be a part of the research study before starting the online survey.

Data Collection Materials

REDCap

REDCap (Research Electronic Data Capture) was used to develop and distribute the online survey. REDCap is a software that allows for electronic and secure collection of data for research purposes. Data from REDCap were exported into SPSS (Statistical Package for the Social Sciences) for analysis. REDCap was introduced to the University of Utah College of Nursing in 2009.

SPSS

SPSS 22 was used to analyze the online survey data. SPSS is comprehensive statistical software used to analyze data. Descriptive statistics, bivariate statistics, linear regression, and factor analysis can be performed using this software.

Procedure

To accomplish Specific Aim 1, REDCap was utilized to administer the online survey (see Appendix A). Potential participants were recruited from two diabetes specific SNS (TuDiabetes and Diabetic Connect), and two general SNS (Facebook and Twitter). Participants provided informed consent prior to completion of the online survey. Once all participants were recruited for this study, the link for the online survey was disconnected. Data were then exported from REDCap to SPSS version 22 for analysis. Data that were incomplete or inaccurate were corrected or deleted as deemed appropriate. Scores for DOC

intensity (Ellison et al., 2007), bonding and bridging social capital (Williams, 2006), SF-12v2 (Ware et al., 2007), and SCI-R (Weinger et al., 2005) were computed in SPSS.

Analysis

The data were initially cleaned. This included omission of one set of duplicative responses, and recoding of variables per validated scale guidelines. Data were then explored for descriptive information, including frequencies, means, medians, and distributions.

To address Specific Aim 1.1, descriptive statistics utilizing SPSS were provided for demographic characteristics, health history, DOC intensity, DOC engagement, social capital, HRQOL, and diabetes self-care behaviors. To assure the reliability of the each scale, a Cronbach's alpha was calculated for each validated scale used: DOC intensity, DOC engagement, online social capital scale, SF-12v2, and SCI-R. Demographic characteristics included gender, education level, employment status, income, age, ethnicity, race, country/state, living setting, and insurance status. Health history characteristics included type of diabetes, diabetes diagnosis duration, diabetes treatments, reported A1C, type of medical practice used for diabetes care, type of provider used for diabetes care, frequency of provider visits, and complications.

To address Specific Aim 1.2, several statistical analyses were performed. A one sample *t*-test was used to compare the studied sample to norms for diabetes (Ware et al., 2007). A one sample *t*-test was used to compare diabetes

self-care scores in this sample to those in the Weinger et al. (2005) study using the revised scale. Detailed information regarding the variables used in each analysis; which included Pearson's correlation, Chi-square tests, *t*-tests, and Analysis of Variance (ANOVA) are listed in Table 3.1.

To address Specific Aim 1.3, the data collected from the online survey were extensively examined for interactions. A1C was recoded to <7% and ≥7%, which served as the dependent variable in the binary logistic regression analyses noted below. Initially, a step-wise logistic regression was conducted, which allowed for refinement of the variables and greater efficiency by removal of nonsignificant variables. In this stepwise logistic regression, background information (demographics, health history, and reasons to join a DOC) were entered based the principal investigators opinion after discussing the topic with DOC opinion leaders and the research team. Nonsignificant variables were removed. Simultaneous logistic regression was then employed in the final predictive binary logistic regression model to predict the probability that A1C would be <7% or ≥7% while controlling for all other variables in the model. An A1C of <7% is the recommended glycemic goal for nonpregnant adults with diabetes (American Diabetes Association, 2014) For inference, *p* values less than .05 were taken as statistically significant.

Table 3.1
Analyses for DOC Intensity, DOC Engagement and Other Variables

Research Question	Measure	Variable	Analysis
What is the difference in HRQOL in this sample and a population norm?	SF-12v2	Continuous	Confidence Intervals, One-Sample *T*-Test
What is the difference in diabetes self-care behaviors in this sample and a population norm?	SCI-R	Continuous	Confidence Intervals, One-Sample *T*-Test
Does DOC intensity/engagement differ by age group and generation?	Generation	Nominal and Ordinal	Confidence Intervals, ANOVA
What gender is more intensely using/engaged with the DOC?	Gender	Nominal	Confidence Intervals, Independent *T*-Test
Does DOC intensity/ engagement differ by type of diabetes?	Type of diabetes	Nominal	Confidence Intervals, ANOVA
What is the relationship between DOC intensity/ engagement and length of diabetes diagnosis?	Length of diabetes diagnosis	Continuous	Pearson's Correlation
Is there a difference between DOC intensity/ engagement among the different categories of diabetes treatments?	Diabetes treatments	Nominal	Confidence Intervals, ANOVA
Does DOC intensity/ engagement differ by reported A1C?	Reported A1C	Nominal	Confidence Intervals, ANOVA
What is the relationship between DOC intensity/ engagement and HRQOL?	SF-12v2	Continuous	Pearson's Correlation

Table 3.1
Cont'd.

Research Question	Measure	Variable	Analysis
What is the relationship between DOC intensity/engagement and bonding and bridging social capital?	ISCS	Continuous	Pearson's Correlation

Note. *HRQOL = Health-related quality of life

Specific Aim 2

Determine how baby boomers describe their experience with the DOC.

Specific Aim 2.1

Describe why baby boomer DOC users participate in the DOC.

Specific Aim 2.2

Describe how DOC users interact with their healthcare providers.

Specific Aim 2.3

Describe how baby boomers anticipate they would continue using the DOC as they aged.

Specific Aim 2 Methodology

Specific Aim 2 addressed baby boomers who engaged in the DOC. In this study, baby boomers DOC users were interviewed to better understand why they participated in the DOC, how this was or was not related to their relationship with their healthcare providers, and if there were plans to continue using the DOC aging forward. The analysis and findings conducted from Specific Aim 2 provided the basis for the second article, Chapter 4.

Design

A qualitative descriptive design was utilized to address Specific Aim 2. Qualitative description is an important research methodology used to comprehensively summarize and describe a phenomenon (Sandelowski, 2000). Reliability and validity of qualitative methodology are based upon trustworthiness of the research methods and the rigor and quality of the qualitative paradigm (Golafshani, 2003). Descriptive validity is present when data are described accurately and in sequence while interpretive validity is when the researcher is able to properly describe the meanings participants attributed to the phenomenon (Morgan, 1993; Sandelowski, 2000). A semistructured interview guide with probes (see Appendix B) was created through a review of literature and input by the research team.

Setting

As noted in Specific Aim 1.

Sample

The sample included baby boomers (born between 1946-1964) from Specific Aim 1. Typically a sample size of 20 or so is needed for saturation in qualitative descriptive research (Green & Thorogood, 2013). Therefore, the target sample to address Specific Aim 2 was 20. A deliberate over-sampling of interviews took place in order to assure there were 20 completed interviews to be analyzed.

Recruitment

At the end of the online survey, participants who were born between 1946 and 1964 were invited to provide an email address and/or phone number if they were interested in participating in the qualitative arm of the study. Participants understood that by submitting personal information they would be contacted at a later date to discuss the objective of the qualitative research and schedule the interview. At the beginning of the call, the interviewer reviewed the study and stated that the interview would be recorded; those willing to participate gave verbal informed consent. Interviewed participants were made aware that a $20 donation would be given to the Diabetes Hands Foundation in recognition for their time.

Informed Consent

All participants provided verbal consent occurred before data collection began.

Data Collection Materials

A digital audio recorder was used to record telephone interviews. To optimize recording, the telephone interviews were conducted via speakerphone.

Procedure

Potential baby boomer participants were recruited for the qualitative arm of the study upon completion of the online survey. Interested participants left

contact information, which was safeguarded on a password protected computer to address privacy issues. Participants were contacted by email to be detailed on the study, provide information about informed consent, and schedule the interview. After obtaining consent, participants were informed that they did not have to answer any question they did not feel comfortable answering and could end the interview at any time. The interview guide probes (see Appendix B) were used. A telephone and digital audio recorder were utilized to conduct and record the qualitative interviews. All interviews were either transcribed verbatim by hired personnel and reviewed for accuracy by the principal investigator, or transcribed verbatim by the principal investigator.

Analysis

The interviews were analyzed using content analysis. Content analysis is a general method for analyzing text-based, verbal or visual communication (Elo & Kyngäs, 2008) and uses a consistent set of codes to organize similar data (Morgan, 1993). Specific Aim 2 used an inductive conventional approach to identify how baby boomers described their experience with the DOC. Inductive content analysis is performed when there is no or little research in the area of interest, while deductive content analysis is useful when previous knowledge has been identified, within the phenomenon of interest (Elo & Kyngäs, 2008). There are three approaches to content analysis when coding and interpreting the data: 1) conventional, 2) directive, and 3) summative. In a conventional approach, coding categories come directly from the text. Directive content analysis utilizes a

theoretical framework as a guide for initial codes. Finally, in a summative approach the text is counted and compared, then interpreted (Hsieh & Shannon, 2005).

Transcripts were read and re-read to generate the codes by the principal investigator. The codes were then systematically applied to the transcripts to determine if any additional codes emerged from the data that needed to be added to the codebook (Morgan, 1993; Sandelowski, 2000). The data were then retextualized to develop corresponding themes (Tesch, 1990). To establish credibility and auditability of the coding, the coding for the first four transcripts were reviewed and verified by the principal investigator and dissertation committee members Drs. Linda Edelman and Erin Rothwell.

Specific Aim 3

Examine how DOC users describe credibility, help, and harm within the DOC.

Specific Aim 3.1

To describe the source credibility of the DOC.

Specific Aim 3.2

To examine differences in DOC source credibility, help, and harm among baby boomers and younger adult (born 1965-1980) counterparts.

Specific Aim 3.3

To describe if baby boomer DOC users view the DOC as an apomediated environment with regard to credibility.

Specific Aim 3 Methodology

Specific Aim 3 used a mixed methods approach, utilizing online survey and interview data. The theoretical underpinnings of apomediation theory, specifically as it relates to credibility issues (see Table 1.1), was used to provide a framework. The findings from Specific Aim 3 were used to develop the third manuscript, Chapter 3.

Design

A concurrent mixed method approach was taken to sequentially capture data with regard to credibility within the DOC.

Setting

As described in Specific Aim 1.

Sample

As described in Specific Aims 1-2.

Recruitment

As described in Specific Aims 1-2.

Informed Consent

As described in Specific Aims 1-2.

Data Collection Materials

As described in Specific Aims 1-2.

Procedure

Online survey and interview data were collected as noted above in Specific Aims 1-2. Results from the source credibility scale (McCroskey & Teven, 1999) were used to calculate 6 individual factor scores: DOC competence factor, DOC caring/goodwill factor, and DOC trustworthiness factor; and diabetes healthcare team competence factor, diabetes healthcare team caring/goodwill factor, and diabetes healthcare team trustworthiness factor. A Cronbach's alpha was conducted to determine reliability of each of the 6 factors.

Interviews were transcribed as noted above in Specific Aim 2. Data specific to credibility were extracted from the transcripts and organized in a separate document to be further examined.

Analysis

Analyses were conducted to examine associations between the individual DOC source credibility factors (competence, caring/goodwill, and trustworthiness and demographic factors, health history, DOC intensity, DOC engagement, social capital, HRQOL, and diabetes self-care). Analyses included Pearson's

correlations, Chi-square, *t*-tests, and Analysis of Variance. DOC source credibility factors were individually compared to the diabetes healthcare team source credibility factor using paired *t*-tests to determine if DOC users found one more credible than the other. Dependent variables also included DOC help or harm in which analyses were conducted to explore relationships with demographic variables, health history, DOC intensity, DOC engagement, social capital, HRQOL, and diabetes self-care. *T*-tests and chi square tests were conducted to determine characteristics and health indicators that differed among baby boomers and a younger adult cohort. For inference, *p* values less than .05 were taken as statistically significant.

Using a qualitative approach, a directive content analysis was used to analyze the text. Directive content analysis utilizes a theoretical framework as a guide for initial codes (Hsieh & Shannon, 2005). The credibility issues identified in Apomediation Theory (Eysenbach, 2008) provided the framework for the coding schema. The researcher read and re-read the interviews to become familiar with the data, indexed the codes according to the theory, created charts to organize data within the thematic framework to allow for data synthesis, then interpreted the data (Lacey & Luff, 2001; Pope, Ziebland, & Mays, 2000; Ritchie & Spencer, 2002). The researcher used reflexivity, the process of systematically documenting the context of knowledge construction and how this knowledge is affecting the researcher (Cohen & Crabtree, 2006),using a reflexive journal to mitigate principal investigator bias.

Human Subjects Protection

The protection of the rights of this population was safeguarded throughout this study. The study was reviewed and approved as exempt by the University of Utah Institutional Review Board (IRB). The principal investigator completed the IRB Collaborative Institutional Training Initiative through the University of Utah. Further, approval for research was provided by the administrative teams for TuDiabetes and Diabetic Connect. The human participants were members of the DOC, including but not limited to members of TuDiabetes, Diabetic Connect, Facebook, and Twitter. To be included subjects must have had a diagnosis of diabetes, be a member of a DOC, and have the ability to read and write English.

There were minimal risks for those participating in this study. This study involved the administration of the online survey to a research posting on TuDiabetes that was shared on Diabetic Connect, Facebook, and Twitter. The online survey included 129 questions, baby boomers who completed the study were asked to participate in a telephone interview. Those completing the online survey had the risk of slight eye strain from viewing the computer monitor. There was small risk that an individual could feel distress, fatigue, or inconvenience due to time spent talking with the researcher during interviews. Breach of confidentiality is another risk that was protected against.

Every possible safeguard was utilized to protect subject identification. A description of the study was provided with notification that the project involved research and that participation is voluntary. Participants were given the contact information of the researcher and were encouraged to ask questions.

Participants who requested specific sections of the interview not be used for the study, for fear of identification, were not included in the analysis. Privacy of interviews was assured by the use of a secure telephone connection. If the participants wished to interrupt, discontinue or delay their interview they were allowed to do so at any time. No identifying data were needed, or used, for the analysis.

All online surveys and transcripts were only identified by a participant number code. The master list of the codes and the corresponding anonymous participant and all other study files including audio files were maintained in a password protected electronic file on a secure computer at the researcher's home. Only the principal investigator had access to identifying data.

Potential Benefits of Human Subjects Involvement

There are many stakeholders who may benefit from this research. Once disseminated, study results will inform patients with diabetes, the DOC, theorists, diabetes treatment providers (physicians, nurse practitioners, physician assistants, certified diabetes educators, registered nurses, registered dietitians, mental health professionals, etc.), hospitals and clinics, state health departments, and professional organizations about peer health, and the relationship between DOC users and health indicators.

Importance of Knowledge To Be Gained

The results of this study enhance the science and understanding of peer-to-peer health within the DOC, and its relationship between DOC intensity and engagement and health indicators among DOC users. In addition, informs stakeholders, including healthcare providers, about DOC use among a baby boomer cohort and aging implications. Further, this research examines credibility and Apomediation Theory through a mixed method manner in order to triangulate data. The results of this study have the potential to significantly contribute to the fields of diabetes, chronic disease, aging and e-health.

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CHAPTER 4

ENGAGEMENT IN THE DIABETES ONLINE COMMUNITY IS ASSOCIATED WITH BETTER GLYCEMIC CONTROL

Abstract

Diabetes requires ongoing self-care management and many individuals with diabetes become experts in translating diabetes care recommendations into real-life strategies to manage their diabetes day-to-day. The diabetes online community (DOC) comprises multiple websites that include social media sites, blogs, and forums in which apomediated diabetes related discussions occur with peers. Online communities have been shown to provide disease specific practical advice, emotional support, shared experience, and encourage empowerment; however little is known about how DOC use is associated with diabetes self-management. The purpose of this study was to explore who uses the DOC, how it is used, and the perceived benefits of DOC use in relation to health indicators.

An online survey was conducted among four DOC sites over a 7-month period in 2012-2013. Chi tests were performed to identify differences in categorical data while *t*-tests and analysis of variance tests were used to identify significant differences between interval data. Binary logistic regression was performed to determine the extent to which DOC use predicted an A1C < 7 or ≥

7% controlling statistically for other variables in the model.

A total of 183 adults participated in this study. The majority were female (71.6%), undergoing intensive insulin management (80.3%), with a mean age of 44.7 (*SD*=14). Participants had high diabetes self-care (*M*=72.4, *SD*=12.1), health-related quality of life (SF-12v2 physical component summary *M*= 64.8, *SD*=19; mental component summary *M*= 66.6, *SD*=21.6), and bonding (*M*=3.1, *SD*=0.64) and bridging (*M*=3.7, *SD*=0.68) social capital scores. DOC engagement was a strong predictor of A1C, reducing the odds of having an A1C ≥7% by 33.8% for every point increase in DOC engagement. Conversely, participants who reported the DOC helped them learn about strategies to improve insurance coverage for diabetes related medications, supplies, and technology devices had a 2.7 times increased odds of having an A1C ≥7%.

The results of this study suggest that individuals highly engaged with the DOC are more likely to have better glycemic control. Further, DOC users have high health-related quality of life and diabetes self-care levels. Participants found online peer health to be beneficial with regard to knowledge and support. DOC members are often not informing their healthcare providers about their DOC participation. Supplementing usual healthcare activities with DOC engagement may encourage knowledge and support among a population who need to optimize diabetes self-management. Further studies are needed to determine how participation with the DOC affects health outcomes.

Introduction

Diabetes is a chronic condition that requires ongoing attention and care. Although both patients and medical providers have responsibilities in diabetes management, patients are necessarily responsible for the vast majority of tasks and decisions in the day-to-day management of diabetes. Supporting patients in self-management is critical because patients who are knowledgeable about managing their own diabetes have better glycemic control (Colleran, Starr, & Burge, 2003; McPherson, Smith, Powers, & Zuckerman, 2008). Further, patients who are actively engaged with their health have better communication with their healthcare provider (Lorig et al., 1999) are more likely to follow recommended testing procedures and medical advice (Remmers et al., 2009), have improved health status (Lorig et al., 2001, 1999) and have fewer healthcare expenditures (Lorig et al., 2001, 1999; Remmers et al., 2009) than those who are not engaged. Therefore, healthcare providers should support patients in improving their knowledge about diabetes, including practical day-to-day diabetes management skills. One mechanism to promote improved self-management and knowledge about diabetes is through the use of resources on the Internet.

The Internet is increasingly used as a source for health information. According to the Pew Research Center Internet & American Life Project, 79% of adults are using the Internet and, of those, 59% are looking for health information (Fox, 2011a). In fact, 23% of individuals with chronic conditions look online to find someone with similar health concerns (Fox, 2011b). The U.S. Department of Health (US Department of Health & Human Services, 2006), recognized that e-

health and Web 2.0 resources, health-related websites that allow for interaction and crowdsourcing content among users, can help patients manage their own health by providing tools for health promotion and disease self-management, access to healthcare records, decision support, support for behavior change, and access to online communities. However, measuring meaningful e-health engagement can be somewhat difficult (Korda & Itani, 2013).

Online health communities can improve social capital (Maloney-Krichmar & Preece, 2005). Social capital, a term coined by Putnam (1995), is comprised of the social connections, networks, and trust that allow individuals to work together as a community. There are two types of social capital. Bonding social capital includes close family and friends and is exclusive. Bonding social capital promotes group cohesion and social support. Bridging social capital is inclusive and is made up of heterogeneous networks of connections with weak ties. Bridging social capital allows for diffusion of information and diverse perspectives (Putnam, 2000). A number of studies have found an association between social capital and health and/or mortality (Hamano et al., 2011; Kawachi, Kennedy, & Glass, 1999; Kawachi, Kennedy, Lochner, & Prothrow-Stith, 1997; Rose, 2000). Among those with chronic conditions, including diabetes, having a large network of social connections is associated with better self-management, physical and mental well-being, and coping with their condition (Reeves et al., 2014). Lack of social capital has been identified as a barrier in diabetes self-management (Henderson, Wilson, Roberts, Munt, & Crotty, 2014).

Due to the complex nature of diabetes, some people find peers helpful in providing social support in the self-management of their disease. A task force jointly convened by the American Association of Diabetes Educators and the American Diabetes Association (Funnell et al., 2012) recognized peer health as an important factor in diabetes management, although in the context of having a healthcare provider facilitate or monitor the peer health discussions. Further, peers who have received special training have been utilized to provide assistance in day-to-day chronic disease management, encourage appropriate clinical care, and offer ongoing social and emotional support (Brownson & Heisler, 2009; Fisher et al., 2012). In diabetes, trained peers have been used for formal face-to-face support/discussion groups (Fisher et al., 2012; Lorig, Ritter, Villa, & Armas, 2009), phone calls (Fisher et al., 2012; Heisler & Piette, 2005; Heisler, Vijan, Makki, & Piette, 2010), text support and home visits (Fisher et al., 2012). Diabetes related peer health has been associated with increased knowledge (Brown, Garcia, Kouzekanani, & Hanis, 2002; Lujan, Ostwald, & Ortiz, 2007), self-efficacy (Heisler & Piette, 2005; Lorig et al., 2010, 2009), patient activation (Lorig et al., 2010, 2009), communication with physicians, healthier eating habits (Lorig et al., 2009), and improved A1C (Gilmer, Philis-Tsimikas, & Walker, 2005; Heisler et al., 2010; Liebman, Heffernan, & Sarvela, 2007; Lorig et al., 2010; Lujan et al., 2007; Markowitz & Laffel, 2012; Moore & Mengel, 2002; Thompson, Horton, & Flores, 2007; Two Feathers et al., 2005). Importantly, reciprocal peer support has been found to be better than nurse care management with regard to A1C reduction (Heisler et al., 2010).

Diabetes Online Community (DOC)

The DOC is a grassroots community developed by people affected by diabetes with the purpose of sharing diabetes knowledge and support based upon their experience living with diabetes. Individuals involved in the DOC typically have diabetes themselves, or are a close family member or friend. More recently professional organizations, healthcare providers, diabetes device companies and pharmaceutical companies have become increasingly involved in the DOC to better understand needs and discussion points among DOC users. It is unknown how many individuals are involved with the DOC due to the vast number of DOC sites and the ability for DOC users to share information across several social media platforms at once. However, the DOC does encompass international users and appears to be growing. Although the DOC has been around for several years, to date there is no formal or academic definition of the DOC.

DOC sites can be moderated (i.e., TuDiabetes, Reality Check) or unmoderated (i.e., Facebook, Twitter). Administrators or volunteers who moderate diabetes specific DOC sites welcome new members, contribute to discussions, provide links to credible information, and address inappropriate advertising and behavior (Gilbert, Dodson, Gill, & McKenzie, 2012). No matter the moderation status, the DOC provides a vehicle for individuals to learn practical diabetes management techniques from peers with shared experiences (Cooper & Kar, 2014; Farrell, 2014), and can be a source of confidence in diabetes management, (Shaffer-Hudkins, Johnson, Melton, & Wingert, 2014)

inspiration, motivation, encouragement (Collins & Lewis, 2013). The DOC includes many Web 2.0 applications including blogs, online video vlogs, discussion boards, and diabetes-specific (i.e., TuDiabetes or Diabetic Connect) and general social media sites (i.e., Facebook, Twitter, or Instagram).

Diabetes-specific discussion boards can be found in standalone websites or embedded within a social media site and participants can either actively contribute to discussions or passively view posts without contributing to the discussion (Sparud-Lundin, Ranerup, & Berg, 2011). These discussion boards are highly valued among individuals in the DOC (Armstrong & Powell, 2009; Jennings, Powell, Armstrong, Sturt, & Dale, 2009) for their diabetes specific practical advice (Armstrong, Koteyko, & Powell, 2012; Greene, Choudhry, Kilabuk, & Shrank, 2011; Ravert, Hancock, & Ingersoll, 2004; Zhou, Sun, & Yang, 2014), emotional support (Armstrong et al., 2012; Gilbert et al., 2012; Greene et al., 2011; H. J. Oh & Lee, 2012; Ravert et al., 2004; Zhou et al., 2014; Zrebiec & Jacobson, 2001), shared experience (Gilbert et al., 2012; Ravert et al., 2004; Zhou et al., 2014), improved coping (Zrebiec, 2005) and empowerment (H. J. Oh & Lee, 2012). Research within diabetes social media sites has found that misinformation is infrequent (Armstrong et al., 2012; Greene et al., 2011; Hoffman-Goetz, Donelle, & Thomson, 2009) and quickly corrected by other members in the discussion group (Armstrong et al., 2012; Gilbert et al., 2012).

Currently there is no research examining the relationship between DOC engagement and health behaviors. The purpose of this study was three-fold: 1) to describe DOC users in terms of demographics, diabetes type, and treatment;

2) to describe intensity of use and levels of engagement of DOC users; and 3) to examine the relationship between DOC use and health-related quality of life, social capital, self-care behaviors, and A1C levels.

Methods

We conducted a cross-sectional study of DOC users using an online survey posted to several DOC social media sites. The study was approved by the University of Utah Institutional Review Board, Salt Lake City, UT. The study was also approved by the administration team from each of the diabetes-specific social media sites on which we recruited participants.

Sample

Adult DOC members, 18 years and older, with a diagnosis of diabetes who could read English were invited to participate in the survey. Any participant who identified themselves as being a caregiver for someone with diabetes (i.e., parent who has a child with diabetes) or less than 18 years old was omitted from the analysis.

Survey Development

A pilot study of DOC users (*n*=5) and diabetes specialty healthcare providers (*n*=2) helped guide the development of the survey (see Appendix C). Pilot participants were asked to determine if any questions were ambiguous or irrelevant, if choices were inappropriate, if any questions were offensive, if there

were questions to add, and how long it took them to complete the survey. The pilot study reflected the need to reword several items in order to enhance and clarify understanding of the items. The final 129-question survey included seven sections: demographic information, health history, health-related quality of life , Web 2.0 application use, reasons to join a DOC, source credibility, and diabetes self-care behaviors.

Demographics

Demographic data (11 items) included gender, marital status, education level, employment status, annual house hold income, age, ethnicity, race, country/state, living setting, and health insurance status.

Health History

Eight questions were dedicated to health history variables: type of diabetes, age when diagnosed with diabetes, current diabetes treatments, most recent A1C, type of medical practice and provider used for diabetes care, frequency of diabetes provider visits, and diabetes complications. Diabetes treatments were broken down into four categories: no treatment, oral agents only, one injected medication with or without oral agents, and intensive insulin management.

Web 2.0 Application Use

Twenty-two individually scaled items, developed by the investigator, were related to how the participants navigate social media applications, if the DOC has helped or harmed the participant, or anyone they knew, and if the participant's healthcare provider supports their DOC use.

Reasons to Join a DOC

Thirteen items were developed based on an anecdotal dLife (Diabetes Life) article (Hernandez, 2009) that addressed the reasons why someone with diabetes should join the DOC. Items were dichotomous, allowing a yes/no response.

DOC Intensity Scale

The DOC Intensity Scale is an 8-item tool adapted from the Facebook Intensity Scale (Ellison, Steinfield, & Lampe, 2007), which was created to measure how often and for how long individuals were engaging with Facebook in order to determine emotional connectedness to the site and how Facebook was integrated into daily activities (Cronbach's alpha = 0.83) (Ellison et al., 2007). The DOC Intensity Scale measures DOC usage, active engagement in the DOC, the number of DOC friends, hours spent on the DOC, and emotional connection to the DOC. The 5-point Likert DOC Intensity Scale is calculated by taking the mean of scores on all items in the scale, resulting in a continuous variable ranging from 0-5.

DOC Engagement

DOC engagement was measured by asking 5 dichotomous yes/no questions related to whether or not participants: shared clinical information, requested or provided clinical guidance or feedback, and received or provided emotional support. Findings from a qualitative analysis of types of posts from DOC users on Facebook informed the development of these questions (Greene et al., 2011). A DOC engagement score was obtained by summing the number of yes responses for the 5 variables. Scores ranged from 0 indicating low engagement to 5 indicating high engagement.

Internet Social Capital Scale

The Internet Social Capital Scale (ISCS) is designed to measure bonding and bridging social capital in both online and offline environments using a 5-point Likert scale to measure either broad Internet use or more specific Internet activities, such as DOC use (Williams, 2006). The original study using the scale reported a Cronbach's alpha of 0.90 for the online survey, which measured both broad and specific Internet use (Williams, 2006). For this study, the question on the bonding subscale, "If I needed an emergency loan of $500, I know someone on the online I can turn to" was changed to "If I needed an emergency loan of diabetes supplies, I know someone on the DOC I can turn to." Three additional questions from the ICSC bonding subscale that did not pertain to the study population were omitted with permission from the original scale designer (Williams, 2006). The adapted 7-item bonding social capital scale and 10-item

social capital scale are scored by computing the mean scores; each domain score has a possible range of 0-5 with higher scores indicating higher levels of social capital.

Health-Related Quality of Life

The SF-12v2 health survey, with a 4-week recall, was used to measure health-related quality of life (HRQOL). The SF-12v2 is the second version of the SF-12, originally developed in 1994 to measure health-related quality of life through physical and mental component summaries of 8 health domains of HRQOL (Ware, Kosinski, Turner-Bowker, & Gandek, 2002, 2007). Norm based scoring (M= 50, SD=10) was used for this analysis (Ware et al., 2007). When tested in the general population in the United States, the Cronbach's alpha ranged between 0.73 and 0.87, with the mean physical component summary being 0.89 and mental component summary being 0.86 (Ware et al., 2007).

Diabetes Self-Care Behaviors

The Self-Care Inventory was originally developed by La Greca and colleagues (1988) and later revised (Weinger, Butler, Welch, & La Greca, 2005) to measure diabetes self-care behaviors. The 15-item Likert scale Self-Care Inventory Revised measures diabetes self-care behaviors, accommodating for the natural variation in treatment plans for patients with type 1 or type 2 diabetes, and duration since diagnosis. The Self-Care Inventory Revised is scored between 0-100, a higher score indicating more self-care. The Cronbach's alpha

for the Self-Care Inventory Revised in a study including 3 datasets was 0.85 (Weinger et al., 2005).

Survey Recruitment and Dissemination

The survey was maintained and disseminated using Research Electronic Data Capture (REDCap) Survey software (Nashville, TN). REDCap Survey is a secure, web-based tool used to create and manage online surveys.

Adult DOC members were recruited in two waves. Initially a synopsis of the study with a link to the survey was posted on the principal investigator's profile page within a diabetes-specific social media site. The viral nature of social media and interest among DOC members allowed for enhanced marketing of the survey. In the early stages of recruitment, members within the social media site posted some negative comments about the study and the principal investigator; these comments may or may not have affected a subsequent slowing in recruitment. To promote recruitment, the social media site administrative team made a comment on the post about the importance of this research and additional advertisement was placed in the social media site online newsletter 4 weeks after the original post. After 3 months a second wave broadened recruitment to include one additional diabetes specific social media site, as well as Facebook, and Twitter. Data were collected within a 7-month timeframe. Potential participants were made aware that a $2 donation would be given to a nonprofit DOC organization for every survey completed up to $1,000. Respondents were not identifiable unless they submitted information to be

contacted for the qualitative arm of the study. Identifiable information was safeguarded using a password protected computer. When potential participants accessed the survey, consent information was provided and a “yes” response was required before they could proceed with the survey.

Data Management

Survey responses were identified by a participant number code and all study related files were maintained in REDCap. In accordance with standard scoring methods, missing data were imputed with appropriately scaled item means in the calculation of total scores for the validated scales. All other missing data were excluded pairwise when conducting analyses. Missing data made up less than 10% of each analysis.

Statistical Analysis

The primary outcomes for this study were to describe DOC users, why and how they used the DOC in terms of intensity and engagement, and the relationship between DOC use and health indicators (health-related quality of life, social capital, self-care, and A1C levels). Statistical analysis was performed using SPSS 21 (IBM Corp., 2012). Exploratory data analysis was conducted to screen for errors, determine frequencies, and identify normality of distribution patterns. Analyses were conducted to determine relationships between and interactions among demographic variables, health history, health-related quality of life, Web 2.0 application use, social capital, DOC intensity, DOC engagement,

and diabetes self-care behaviors. These analyses included correlations, independent and one sample *t*-tests, ANOVAs (followed by LSD-adjusted post hoc tests, where appropriate), and logistic regression. For inference, *p* values less than .05 were taken as statistically significant.

The variables that predicted the dichotomous outcome of A1C being <7% or ≥ 7% were examined in a simultaneous model among DOC users. To explore this, variables were analyzed based on researcher and DOC opinion leader suggestion in an initial step-wise logistic regression. Step-wise logistic regression allowed for refinement of the variables and greater efficiency by removal of nonsignificant variables. Simultaneous logistic regression was then employed in the final predictive model.

Results

There were 207 survey participants. There were 1501 unique site visitors who viewed the online recruitment post, with 183 responses, for a recruitment rate of 12.2%. After omitting caregivers and minors, the final sample included 183 adults.

Demographics

Participant demographics are shown in Table 4.1. Participants were more likely to be female, White, living in the United States in a suburban setting, well

Table 4.1
Demographics by Type of Diabetes

Characteristics	Type 1 Diabetes (*n*=129, 69.7%) *n*(%)	Type 2 Diabetes (*n*=33, 17.8%) *n*(%)	LADA[c] (*n*=21, 11.4%) *n*(%)	Total (%)	*P*
Age, mean (*SD*)[a]	41 (13.6)	51.2 (11.4)	52.6 (13.7)	44.7 (14.0)	.000
Diagnosis Duration in years, mean (*SD*)[a]	22.5 (14.6)	6.4 (5.7)	10.4 (10.2)	18.2 (14.6)	.000
Gender, No. (%)[b]					.087
Male	31(24.4)	14(42.4)	4(20)	26.8	
Female	96(75.6)	19(57.6)	16(80)	71.6	
Ethnicity, No. (%)[b]					.267
Hispanic or Latino	6(4.7)	0(0)	0(0)	3.3	
Not Hispanic or Latino	121(95.3)	33(100)	21(100)	95.6	
Race, No. (%)[b]					.728
AI or AN[d]	2(1.6)	0(0)	0(0)	1.1	
Asian	2(1.6)	0(0)	1(5)	1.6	
African American	2(1.6)	0(0)	0(0)	1.1	
White	122(95.3)	33(100)	19(95)	95.1	
Country, No. (%)[b]					.640
United States	108(84.4)	27(81.8)	16(76.2)	82.5	
Not United States	20(15.6)	6(18.2)	5(23.8)	16.9	
Living Setting, No. (%)[b]					.025
Rural	16(12.4)	11(33.3)	6(28.6)	18.0	
Suburban	78(60.5)	16(48.5)	8(38.1)	55.7	
Urban	35(27.1)	6(18.2)	7(33.3)	26.2	
Income, No. (%)[b]					.582
Less than $30,000	28(23)	12 (36.4)	3(16.7)	23.5	
$30,000-$49,999	20(16.4)	5(15.2)	5(27.8)	16.4	
$50,000-$74,999	24(19.7)	6(18.2)	4(22.2)	18.6	

Table 4.1
Cont'd.

	Type 1 Diabetes (*n*=129, 69.7%) *n*(%)	Type 2 Diabetes (*n*=33, 17.8%) *n*(%)	LADA[c] (*n*=21, 11.4%) *n*(%)	Total (%)	*P*
Education, No. (%)[b]					.001
Some High School	2(1.6)	0(0)	0(0)	1.1	
High School Graduate	5(3.9)	6(18.2)	0(0)	6.0	
Some College	13(10.2)	7(21.2)	8(38.1)	15.3	
Associates Degree	11(8.6)	6(18.2)	3(14.3)	10.9	
Bachelor's Degree	54(42.2)	8(24.2)	4(19)	36.1	
Graduate Degree	43(33.6)	6(18.2)	6(28.6)	30.1	
Employment, No. (%)[b]					.191
Student	12(9.3)	2(6.1)	1(5)	8.2	
Unemployed	8(6.2)	5(15.2)	1(5)	7.7	
Working Part-Time	20(15.5)	4(12.1)	3(15)	14.8	
Working Full-Time	67(51.9)	13(39.4)	10(50)	49.2	
Retired	9(7)	6(18.2)	5(25)	10.9	
Disabled	13(10.1)	3(9.1)	0(0)	8.7	
Insurance, No. (%)[b]					.625
Insured	111(92.5)	32(97)	19(95)	88.5	
Uninsured	9(7.5)	1(3)	1(5)	6.0	

[a] Analysis of variance
[b] Chi-Square
[c]Latent autoimmune diabetes of adulthood
[d]American Indian or Alaskan Native

educated, employed, and to have type 1 diabetes. Age ranged from 18-82, with a mean age of 44.7 (*SD*=14) and median of 45 years. When age was categorized by generation, 24% identified as millennial/generation Y (born after 1980), 31.7% identified as generation X (born between 1965-1980), 41.5% identified as baby boomers, (born between 1946-1964), and 2.7% identified as the silent generation (born between 1925-1945). Participants with type 1 diabetes were significantly younger than those with type 2 diabetes ($p<.001$) and latent autoimmune diabetes of adulthood (LADA) ($p<.01$).

Health History

Most of the participants sought care for their diabetes at an endocrinology office (68.1%), although those with type 2 diabetes more likely to be seen by a family practice provider ($p<.001$) than those with type 1 diabetes. Participants were seeing their healthcare providers at least quarterly (67.4%) or every 6 months (23.8%) and had an average of 1.2 complications. There was a positive correlation between diabetes duration and number of complications ($r= .369$, $p<.001$). Those with type 1 diabetes were more likely to report depression ($p<.01$), heart disease ($p<.01$), and eye disease ($p<.001$) than those with type 2 diabetes or LADA. Diabetes treatments varied and ranged from no medications (5.5%), oral agents only (8.7%), one injected medication with or without oral agents (5.5%), and intensive insulin management (80.3%). Of those undergoing intensive insulin management, 54.8% were using an insulin pump while 25.2% were using a continuous glucose monitor. Respondents who had type 1 diabetes

had a significantly longer diabetes duration than those with type 2 diabetes or LADA (p<.001).

Web 2.0 Use

Participants were using an average of 2.6 devices to access the Internet and 4.2 information sources for health information. Participants spent their time reading (91.3%), responding (74.3%), and creating original posts (59.6%). Only 3.8% of the sample reported not reading, responding or creating original posts. The time participants had been using the DOC ranged from less than 1 year (32%), 1-3 years (37.7%), or more than 3 years (30.4%). The majority of respondents had not told their healthcare providers about their DOC use (67.2%), and of those who did tell their healthcare providers about their DOC use, 19.5% were supported to continue doing so, 1.6% were not, and 10.8% were not sure.

Reasons to Join a DOC

The majority of participants found benefits to participating in the DOC as it related to knowledge attainment, support, and empowerment. The percentage of individuals stating yes for each item is listed in Table 4.2.

DOC Intensity

The average DOC Intensity Scale score was 2.76 (SD = .73) with a possible range of 0-5. Cronbach's coefficient for the DOC Intensity Scale was

Table 4.2
Reasons to Join a DOC.

	(%) stating yes
The DOC helps me feel understood	79
The DOC helps me feel less alone	76
The DOC helps me feel more empowered	73
The DOC helps me feel support through rough times	57
The DOC helped me learn new diabetes management strategies	80
The DOC helped me learn research and treatment alternatives	83
The DOC helped me get answers to many of my diabetes questions	76
The DOC helped me learn about potential side effects of drugs or devices	64
The DOC helped me learn things that my healthcare provider didn't know	60
The DOC helped me learn strategies to improve insurance coverage for diabetes related medications, supplies, or tools	48
I discussed a topic I learned about on the DOC with my healthcare provider	48
The DOC allows me to help others.	81
The DOC allows me to make new friends.	66

Note. N=169 to 176

0.85.There was a significant difference in the intensity in which participants were using the DOC when comparing four diabetes treatments $F(3, 177)=3.5$, $p<.05$. Respondents who were on no medications ($M=3.1$, $SD=0.80$) or on intensive insulin management ($M=2.8$, $SD=0.71$) had significantly higher DOC intensity scores when compared to those taking oral agents only ($M=2.3$, $SD=0.69$). There were significant relationships between DOC intensity and all 13 reasons to join a DOC (see Table 4.3). DOC intensity scores varied based upon whether or not DOC users had told their healthcare providers about their DOC use, and if it was supported $F(3, 170)=11.3$, $p<.001$. Specifically, DOC intensity scores were higher in those who had told their healthcare providers about their DOC use and felt supported ($M=3.2$, $SD=0.64$) or weren't sure ($M=3.2$, $SD=0.57$) than those who had never told their healthcare providers about their DOC use at all ($M=2.6$, $SD=0.71$). Type of diabetes or length of time using the DOC did not play a significant role in DOC intensity. DOC intensity and DOC engagement were positively correlated ($r=.572$, $p<.001$).

DOC Engagement

The average DOC engagement score was 2.24 (SD = 1.69) with a possible range from 0-5. Cronbach's coefficient for DOC engagement was 0.73. There were significant positive relationships between DOC engagement and all 13 reasons to join a DOC (see Table 4.3). There were significant differences in DOC engagement scores as it related to healthcare provider knowledge and

support of DOC use $F(3, 170)=11.0$, $p<.001$. DOC engagement scores were higher for those who had told their healthcare providers about their DOC use and were unsure if they were supported (M=2.9, SD=1.3) or felt supported (M=3.6, SD=1.4) than those who had never told their healthcare providers about their DOC use at all (M=1.9, SD=1.6). Engagement scores significantly increased the longer someone had participated in the DOC. Those who had participated in the DOC 4 or more years (M=2.86, SD=1.7) were more engaged than those who had participated less than 3 months (M=1.50, SD=1.5) ($p<.001$). There was no significant difference in DOC engagement scores for those who were insured or uninsured or by type of diabetes. Further, there was no significant correlation between DOC engagement and age, diabetes type, or diabetes duration.

Health-related Quality of Life

The SF-12v2 physical component summary mean score was 64.8 (SD=19) and mental component summary was 66.57 (SD=21.1). Cronbach's coefficient for the SF-12v2 was 0.88 (physical=.77 and mental=.86). The mean physical component summary and mental component summary were both significantly higher ($p<.001$, one sample t-test) than previously reported physical component summary norms of 41.9 and mental component summary norms of 48.1 of individuals with diabetes (Ware et al., 2007). Participants who reported depression had lower SF-12v2 physical component summary scores (no depression M=70.2, SD=15.6; reported depression M=53.2, SD=20.3, $p<.001$) and mental component summary scores (no depression M=74.9, SD=14.8;

Table 4.3
DOC Users Who Reported DOC Benefits and its Relationship to DOC Intensity and Engagement.

DOC Benefit	DOC Intensity			DOC Engagement		
	Mean	*SD*	*p*-value	Mean	*SD*	*p*-value
Feel understood			.000			.000
Yes	3.0	.65		2.7	1.6	
No	2.1	.64		1.2	1.3	
Feel less alone			.000			.000
Yes	3.0	0.62		2.7	1.7	
No	2.2	0.60		1.4	1.2	
Feel more empowered			.000			.000
Yes	3.0	0.63		2.8	1.6	
No	2.1	0.60		1.0	1.1	
Feel support through rough times			.000			.000
Yes	3.1	0.62		2.92	1.6	
No	2.4	0.70		1.57	1.5	
Learn new diabetes management strategies			.000			.000
Yes	2.9	0.67		2.6	1.6	
No	2.1	0.64		1.4	1.4	
Learn research and treatment alternatives			.000			.000
Yes	2.9	0.66		2.6	1.7	
No	2.1	0.70		1.0	0.98	
Get answers to diabetes questions			.000			.000
Yes	3.0	0.65		2.7	1.6	
No	2.2	0.67		1.4	1.4	
Learn about potential side effects of drugs/devices			.000			.000
Yes	3.0	0.65		2.8	1.6	
No	2.3	0.68		1.5	1.4	

Table 4.3
Cont'd.

DOC Benefit	DOC Intensity			DOC Engagement		
	Mean	*SD*	*p*-value	Mean	*SD*	*p*-value
Learn things that my healthcare provider didn't know			.000			.000
Yes	3.0	0.68		2.8	1.6	
No	2.4	0.70		1.5	1.4	
Learn strategies to improve insurance coverage for diabetes related medications/supplies/tools			.000			.003
Yes	3.0	0.66		2.7	1.7	
No	2.5	0.72		2.0	1.6	
Discussed a topic learned from DOC with my healthcare provider			.000			.000
Yes	3.0	0.68		3.2	1.6	
No	2.5	0.68		1.6	1.4	
Help others			.000			.000
Yes	2.9	0.66		2.7	1.6	
No	2.1	0.74		0.70	0.88	

Note. N=169 to 176

reported depression *M*=49.1, *SD*=22, *p*<.001) than those who had no depression. The SF-12v2 physical component summary negatively correlated with age (*r*=-.177, *p*<.05). The physical component summary and mental component summary were not related to diabetes type, DOC engagement, and DOC intensity.

Social Capital

The Internet Social Capital Scale bonding mean score was 3.08 (*SD*=0.64) and bridging mean score was 3.68 (*SD*=0.68). Cronbach's coefficient for the Internet Social Capital Scale was 0.89 (bonding= .69 and bridging= .92). High bonding and bridging social capital correlated with high DOC intensity (*r*=.629, *p*<.001 and *r*=.676, *p*<.001 and respectively) and high DOC engagement (*r*=.474, *p*<.01 and *r*=.507, *p*=<.01 and respectively) (see Table 4.4). Further, high bonding (*p*<.001) and bridging (*p*<.001) social capital was identified in those who reported "yes" to all 13 reasons to join a DOC (see Table 4.5). Bonding (*p*<.001) and bridging (*p*<.001) social capital scores were higher in those who had told their healthcare provider about their DOC use and felt supported (bonding *M*=3.5, *SD*=.63; bridging *M*=4.2, *SD*=.51) or weren't sure (bonding *M*=3.26, *SD*=.57; bridging *M*=3.93, *SD*=.48) than those who had never told their healthcare providers about their DOC use at all (bonding *M*=2.94, *SD*=.59; bridging *M*=3.48, *SD*=.68). There was a negative correlation between bonding social capital and age (*r*=-.200, *p*<.01).

Table 4.4
Correlation Matrix for Health Indicators

		1	2	3	4	5	6	7
1	DOC Intensity	1.00						
2	DOC Engagement	.572[c]	1.00					
3	Physical HRQOL	-.043	.102	1.00				
4	Mental HRQOL	-.076	.074	.651[c]	1.00			
5	Bonding Social Capital	.629[c]	.474[c]	.022	.028	1.00		
6	Bridging Social Capital	.676[c]	.507[c]	-.010	-.014	.679[c]	1.00	
7	Diabetes Self-Care	.236[b]	.170[a]	.097	.301[b]	.127	.234[b]	1.00

[a]Significance at the <.05 level
[b]Significance at the <.01 level
[c]Significance at the <.001 level

Diabetes Self-Care Behaviors

On average, DOC participants had high self-care scores (*M*=72.4, *SD*=12.0) when compared to means scores found in other samples of adults with type 1 and type 2 diabetes (*p*<.001, one-sample *t*-test) (Weinger et al., 2005). Cronbach's coefficient for the SCI-R was .68. Diabetes self-care behavior scores were significantly lower in those who reported depression (no depression *M*=74.1, *SD*=10.8; reported depression *M*=68.9, SD=13.8, *p*<.05).There were significant positive correlations between high self-care scores and high DOC engagement scores (*r*=.170, *p*<.05), high DOC intensity scores (*r*=.236, *p*<.01), and high SF-12v2 mental component summary scores (*r*=.301, *p*<.01). There was a significant negative correlation between high self-care scores and lower

Table 4.5.
DOC Users Who Reported DOC Benefits and its Relationship to Bonding and Bridging Social Capital

DOC Benefit	Bonding Social Capital			Bridging Social Capital		
	Mean	*SD*	*p*-value	Mean	*SD*	*p*-value
Feel understood			.000			.000
Yes	3.2	.61		3.9	.53	
No	2.6	.53		2.9	.64	
Feel less alone			.000			.000
Yes	3.2	.62		3.9	.55	
No	2.7	.48		3.1	.71	
Feel more empowered			.000			.000
Yes	3.3	.62		3.9	.53	
No	2.6	.50		3.0	.62	
Feel support through rough times			.000			.000
Yes	3.3	.58		4.0	.45	
No	2.7	.58		3.3	.71	
Learn new diabetes management strategies			.001			.000
Yes	3.2	.63		3.8	.58	
No	2.7	.63		3.1	.77	
Learn research and treatment alternatives			.000			.000
Yes	3.2	.63		3.8	.60	
No	2.7	.56		3.0	.76	
Get answers to diabetes questions			.000			.000
Yes	3.2	.63		3.8	.56	
No	2.7	.53		3.1	.73	
Learn about potential side effects of drugs/devices			.000			.000
Yes	3.2	.62		3.9	.59	
No	2.8	.63		3.4	.75	

Table 4.5.
Cont'd.

DOC Benefit	Bonding Social Capital			Bridging Social Capital		
	Mean	*SD*	*p*-value	Mean	*SD*	*p*-value
Learn things that my healthcare provider didn't know			.000			.000
Yes	3.2	.63		3.9	.60	
No	2.9	.61		3.4	.72	
Learn strategies to improve insurance coverage for diabetes related medications/supplies/tools			.000			.000
Yes	3.8	.63		3.9	.62	
No	2.8	.55		3.5	.67	
Discussed a topic learned from DOC with my healthcare provider			.000			.000
Yes	3.3	.63		3.9	.57	
No	2.9	.58		3.5	.68	
Help others			.000			.000
Yes	3.2	.61		3.8	.54	
No	2.6	.57		3.0	.87	

Note. N=169 to 176

A1C (r=-.157, p<.05). Correlations between all health indicators studied are presented in Table 4.4.

A1C Levels and Predictors

The majority (59.6%) of survey respondents reported an A1C <7%. There was no statistically significant difference in A1C levels between US and non-US users, insured and uninsured users, or type of diabetes. After conducting an initial step-wise logistic regression, the final predictive binary logistic regression model (see Table 4.6) was employed to explain the A1C category of <7% or ≥7% while controlling for all other variables in the model. The odds ratio for age was significant, with every 1-year increase in age yielding 3.4% reduction in the odds of having an A1C ≥7%. Diabetes duration (coded as the square root of years since diabetes diagnosis to address a positive skew) generated a 1.46 odds ratio of having an A1C ≥7%. DOC engagement (range 0-5) was a strong negative predictor of A1C; every point increase in DOC engagement yielded 33.8% reduction in odds of having an A1C ≥7%. There was a 2.7 times increased odds of having an A1C ≥7% among participants who reported the DOC helped them learn about strategies to improve insurance coverage for diabetes related medications, supplies, and technology devices (coded yes/no).

Discussion

The purpose of this study was to explore who uses the DOC, how it is used, and if the DOC provided any benefits as it related to health indicators.

Table 4.6.
Final Model Explaining Risk of A1C ≥ 7%

	B	Standard Error	*p**	*Exp(B)* = Odds Ratio	95% Confidence Interval for *Exp(B)*	
					Lower	Upper
DOC Engagement[a]	-.413	.132	.002	.662	.511	.857
Diabetes Diagnosis Duration[b]	.377	.108	.000	1.459	1.180	1.803
Learned Insurance Coverage Strategies	.987	.406	.015	2.684	1.212	5.944
Help Others	-.952	.557	.087	.386	.130	1.150
Support through Rough Times	.808	.441	.067	2.243	.946	5.320
Age in years	-.035	.014	.012	.966	.940	.992
Constant	.349	.793	.660	1.417		

**p*-value of Wald ratio.
[a]DOC engagement score, mean score of 5 dichotomous variables, coded 0-5.
[b]Length of time in years since diabetes diagnosis using a square root transformation to address a positive skew.

Below we discuss the significant findings that support both the importance of the DOC for specific populations with diabetes and the positive association of DOC use with health indicators. Implications for practice are also discussed.

We found an overwhelming representation of type 1 diabetes within this sample of DOC users, even though type 1 diabetes makes up only 5-10% of all diagnosed cases of diabetes (US Department of Health & Human Services, 2014). This over representation may be due to the fact that individuals with type

1 diabetes must utilize intensive insulin management techniques while individuals with type 2 diabetes may not or because those with type 1 in this sample were younger and more likely to use social media in general. Intensive insulin management may drive an additional need for knowledge and support, leading patients to the DOC. Further, those with type 1 diabetes have more exposure to technology given that they typically diagnosed much younger and must use a glucometer. Finally, because there are fewer individuals with type 1 diabetes compared to type 2 diabetes in the general population, those with type 1 diabetes may not be able to connect with another person with their same condition offline and this may lead them to seek others like themselves online (Fox, 2011b). Even through there were more individuals with type 1 diabetes than type 2 diabetes or LADA in this study, there was not a significant difference between type as it related to DOC engagement or A1C. A1C levels were also not different between type of diabetes, which may be explained by an internal drive for diabetes management, DOC use, or both.

More of the survey respondents in this study were baby boomers. Baby boomers are the fastest growing group to use social media sites (Zickuhr, 2010). DOC users who were older had better A1C levels, which may be explained by maturity and stability that often comes with age or less severe disease than those who didn't live to older age. In addition, the prevalence of diabetes is rising in the baby boomer cohort (King, Matheson, Chirina, Shankar, & Broman-Fulks, 2013; Martin, Freedman, Schoeni, & Andreski, 2009). With an overwhelming number of individuals turning 65 every day, the baby boomer related aging tsunami is going

to have a huge impact on healthcare system resources. The DOC can fill an important niche in diabetes care, at least in those on intensive insulin management, as it relates to increasing knowledge, improving self-care, providing social support, and having a positive impact on health-related quality of life.

The majority of participants had not told their healthcare providers about their DOC use. While our findings support the idea that DOC use is supplementary to, not in place of, regular healthcare provider visits, research has shown that healthcare providers may be hesitant to suggest DOC use due to concerns about misinformation (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006; Moick & Terlutter, 2012), fearing a power imbalance (Murray, Pollack, White, & Lo, 2007; Snow, Humphrey, & Sandall, 2013) or challenge of authority (Murray et al., 2003). However, there are healthcare providers who support DOC use and some sit on the DOC advisory teams (Diabetes Community Advocacy Foundation, 2014) and board of directors (Diabetes Hands Foundation, 2014). It is important for healthcare providers to be aware of the DOC and how health related social media is driving a more patient-centered healthcare system (Hawn, 2009; van der Eijk et al., 2013) by putting the patient's preferences and values about how they want to receive healthcare front and center (Institute of Medicine Committee on Quality of Health Care in America, 2001). Further, healthcare providers should be learning how they can engage with the DOC themselves while supporting their patients with diabetes to use the DOC (Collins & Lewis, 2013; Cooper & Kar, 2014). It is unknown if all individuals

with diabetes would benefit from peer health (Smith et al., 2011). However, if healthcare providers supported DOC use among their patients, patients would be encouraged to access online diabetes management information and support. In this way, the DOC could be a complementary resource for information not found in the traditional healthcare model. Further, healthcare provider support of DOC use may encourage the development of bonding and bridging social capital, which as discussed below, are associated with better diabetes self-care.

DOC intensity varied by treatment and was related to support. Those with no medications or on intensive insulin management used the DOC more intensely than those on oral agents. This is perhaps due to the fact that individuals on no medications may be accessing the DOC to educate themselves with hopes to halt the progression of their diabetes while those on intensive insulin management require more education, skills, and support to manage their diabetes than those on oral agents only. Similar to other research (Cobb, Graham, Bock, Papandonatos, & Abrams, 2005), this study found associations between intensity of DOC use and feeling supported in disease management. Research has shown that individuals with chronic conditions who were uninsured were more likely than those who were privately insured to be frequent users of online health information (Bundorf, Wagner, Singer, & Baker, 2006). However, this was not seen in this study.

DOC users have higher health-related quality of life when compared to norms for the general population and diabetes (Ware et al., 2007). This finding is supported by research showing that individuals who seek health information

online reported being happier and healthier when compared to those who sought health information offline (Cotten & Gupta, 2004). DOC members can quickly access health related information they desire in multimethod formats (i.e., discussion board, blog, Tweetchat, etc.), allowing them to: 1) easily review crowdsourced information from individuals living with diabetes; 2) learn the same information in a variety of ways (Korda & Itani, 2013) from different DOC users, to address learning style preferences; and 3) focus on topics based on need and interest. The DOC also provides an avenue for individuals with diabetes to provide social support to one another. Social support, which has been linked to health-related quality of life (Aalto, Uutela, & Aro, 1997), allows individuals to feel less alone in their diabetes.

DOC users have high social capital bonding and bridging scores. Those who felt more connected to the DOC reported greater benefits with regard to knowledge attainment, social support, and empowerment. Those with high bridging social capital also had high diabetes self-care scores. Putnam (2001) found that social connectedness strongly predicts of altruism. The overwhelming majority of study participants indicated the DOC allowed them to help others, indicating a sense of altruism among members. Altruism has been identified as a factor in participating in chronic disease online communities (S. Oh, 2012; Reeves et al., 2014; van Uden-Kraan et al., 2008).

This is the first study to demonstrate that engaging in the DOC is associated with positive health benefits for people with diabetes. DOC engagement is related to better glycemic control, self-care, increased knowledge,

and empowerment. DOC engagement allows individuals to share personal experiences, exchange emotional support, and gain expertise in day-to-day management techniques through crowdsourced information by peers. While it is important to note that directionality and causation cannot be determined in this model, there is evidence to suggest that DOC engagement may lead to improved A1C. Individuals with diabetes who are actively engaging in the DOC are actively participating in their own healthcare. Patient activation, which has been seen to decrease healthcare costs, is gauged by knowledge, skills, and confidence one has to manage their own health (Hibbard, Greene, & Overton, 2013). In this study, DOC engagement was associated with increasing diabetes-related knowledge and skills, self-care, and empowerment, which supports the notion of high patient activation. Health literacy may also improve with increased diabetes-related knowledge. Research has shown that the interaction between patient activation and health literacy is associated with glycemic control (Woodard, Landrum, Amspoker, Ramsey, & Naik, 2014). Further, patients who actively participate in medical decisions have improved glycemic control (Greenfield, Kaplan, Ware, Yano, & Frank, 1988). Additional research is needed to distinctly identify how the DOC impacts glycemic control, patient activation, and health literacy.

Diabetes duration and seeking information to get insurance to cover diabetes related healthcare expenses (i.e., medications, test strips, insulin pump, continuous glucose monitor) were positively associated with an A1C ≥7%. In this study, the longer someone lived with diabetes the more likely they were to report

a diabetes related complication. Diabetes related complications can affect glycemic control as it relates to hypoglycemia unawareness, renal function, and other factors. Individuals who have an A1C ≥7 and complications may be participating in the DOC to identify information to support improved glycemic control in order to prevent complication progression. Further, individuals who already had an A1C ≥7% may have sought support from the DOC to learn strategies to improve insurance coverage of diabetes related expenses so they could in turn improve their diabetes management. Longitudinal research is necessary to understand glycemic control as it relates to specifics of DOC use, such as learning how to improve insurance coverage for diabetes related expenses.

The association between DOC engagement and better glycemic control found in this study has clinical significance. Long-term benefits related to the prevention of neurologic, microvascular (The Diabetes Control and Complications Trial Research Group, 1993; UK Prospective Diabetes Study Group, 1998) and macrovascular disease (Nathan et al., 2005; Stettler et al., 2006) have been found in those with tight glycemic control. Participation in the DOC requires no resources to the current healthcare system, although it is only available to those with internet access and the literacy to use it. DOC users whose healthcare providers supported them in their DOC use had higher DOC engagement scores, which may not only supplement diabetes care, but also lead to improved glycemic control. Despite documented benefits (Heisler & Piette, 2005; Heisler et al., 2010; Lorig et al., 2009), there are currently no professional

recommendations for individuals to use peer health via the DOC to supplement their diabetes care.

Limitations

The sample was recruited from the DOC and caution should be made with regard to generalization due to sample self-selection. Individuals who responded to the survey may be more engaged with the DOC or have better glycemic control. The majority of individuals in this sample identified themselves as using intensive insulin management, which does not reflect the same treatment intensity seen in the general population. There were only 12.2% responses based on the number of times the study recruitment post was viewed by unique site visitors. While the recruitment percentage may appear low, a response rate of <.01% is not unusual for online surveys (Eysenbach, 2004). Further, the respondents were overwhelmingly White with most participants living in the United States, which may not be an accurate reflection of the entire DOC population. This study only looked at adult DOC users. Findings should not be generalized to minors or caregivers participating in the DOC. Finally, this study did not specifically identify “lurkers” and how their results might be similar or different.

Self-reporting of A1C may affect reliability of data; however, research has shown that the reliability of self-reported diabetes data is accurate >92% of the time (Schneider, Pankow, Heiss, & Selvin, 2012). Similar A1C results have been found among international DOC users, in which the average A1C was 6.9%

(Weitzman, Adida, Kelemen, & Mandl, 2011). Further, some DOC participants have been found to share their A1C levels with others online (Weitzman et al., 2011), and have gone as far as including a photograph of their lab record. This transparency in sharing health information among some DOC users may improve reliability in reporting, although A1C documentation was not requested for this study.

The nature of this research cannot determine causality. It is unknown if the high DOC engagement results in high self-care and optimal glycemic levels, or vice versa, or if common unknown causal factors induce the association. Prospective studies, specifically randomized control trials, are warranted to better understand the DOC and its impact on health outcomes.

Conclusions

The results of this study suggest that individuals who highly engage with the DOC are more likely to have A1C levels <7% than those who engage less, although directionality cannot be determined. DOC members are generally proactive in diabetes self-care behaviors. There was strong sense of community among DOC participants. Participants found DOC peer health to be beneficial with regard to knowledge attainment and support. DOC members are often times not informing their healthcare providers about their participation with the DOC. Healthcare providers should be familiar with the DOC and inquire of their patients about use of online sources for diabetes management. Supplementing usual healthcare activities with DOC engagement may encourage knowledge and

support among a population to optimize diabetes self-management. This study adds to the body of knowledge in diabetes care and online communities for chronic disease management. Further studies need to be conducted to determine how participation with the DOC affects health outcomes.

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CHAPTER 5

DIABETES ONLINE COMMUNITY USERS EMPOWERED BY RECIPROCAL PEER KNOWLEDGE AND SUPPORT

Abstract

The use of online health communities is growing. Individuals, including baby boomers, with diabetes are participating in the diabetes online community (DOC), although it is unclear how the DOC supports their diabetes care. The aim of this exploratory study was to describe to describe why baby boomers participated in the DOC, how they interacted with their healthcare providers, and how they anticipated they would continue using the DOC as they aged.

Telephone interviews were conducted with 20 baby boomer DOC users living in the United States. Transcripts were developed from the interviews and analyzed using qualitative content analysis. There were six themes that emerged from the data: wisdom from experience, high desire for information to improve self-care, emotional support, belonging to a community, validation of information, and cause for concern.

DOC users highly value the DOC and regard their participation as a vehicle to increase knowledge to improve self-care and reciprocate emotional

support with others who have shared experiences in diabetes management. Participants respected diabetes elders and aspired to become a diabetes elder themselves, anticipating continued use of the DOC aging forward. DOC use was complementary to regular medical provider visits, filling a gap in the current healthcare system. DOC users methodically processed information to determine credibility and relevance to their own situation. While several benefits related to knowledge and support to inform diabetes management were reported, concerns were also mentioned. Healthcare providers should become familiar with the DOC and consider it an important source of information for their aging patients.

Introduction

Diabetes is a complex chronic condition that requires ongoing attention to day-to-day activities in order to achieve adequate glucose management. Individuals with diabetes are expected to spend more than 2 hours per day carrying out recommended self-care (Russell, Suh, & Safford, 2005). The time and intensity in which individuals think about the complexities of diabetes and experience the often unavoidable health fluctuations associated with their condition can be physically and emotionally taxing. Therefore, adequate informational and emotional support is imperative for patients to effectively manage their diabetes (Colleran, Starr, & Burge, 2003; Henderson, Wilson, Roberts, Munt, & Crotty, 2014; McPherson, Smith, Powers, & Zuckerman, 2008).

There has been a paradigm shift in which the patient role has elevated from a passive recipient to an active consumer of healthcare (McMullan, 2006).

As active consumers, patients are seeking more information to assist them in making decisions about their health. This is particularly true for individuals with chronic conditions who need information that will allow them to be successful in disease management long-term.

Peer health and support is gaining traction in chronic disease management as a way for patients to actively seek and engage in healthcare decisions. There are core functions of peer groups: support day-to-day chronic disease management, encourage appropriate clinical care, and offer ongoing social and emotional support (Boothroyd & Fisher, 2010; Brownson & Heisler, 2009; Fisher et al., 2012). Heisler and colleagues (2010) suggest peer interactions between individuals with diabetes provide informational support, emotional support, and mutual reciprocity, which leads to improved diabetes attitudes, diabetes self-care and glycemic control. Peer health can also be used to support life transitions or times of uncertainty (Rasmussen, Dunning, & O'Connell, 2007). Diabetes programs where peers have been trained to be “coaches” or “advisors” for the purpose of peer health, in addition to moderation by healthcare providers, has resulted in increased knowledge (Brown, Garcia, Kouzekanani, & Hanis, 2002; Lujan, Ostwald, & Ortiz, 2007), increased social support (Heisler et al., 2010) and improved A1C results (Brown et al., 2002; Gilmer, Philis-Tsimikas, & Walker, 2005; Heisler et al., 2010; Liebman, Heffernan, & Sarvela, 2007; Lorig et al., 2010; Lujan et al., 2007; Moore & Mengel, 2002; Thompson, Horton, & Flores, 2007; Two Feathers et al., 2005). However, peer education may not be helpful for all individuals with diabetes

(Smith et al., 2011) and a secondary factor that unites peers, such as gender, culture, age, or shared experience (Heisler et al., 2010) may be necessary for optimal outcomes. It is unknown how nonhealthcare provider moderated, nontrained peer interactions, as seen in the diabetes online community (DOC), affect individual and health outcomes.

Diabetes Online Community

There is an increasing number of individuals accessing the Internet for health information; those with diabetes are no different. The DOC is a grassroots community developed by people affected by diabetes with the purpose of sharing diabetes knowledge and support based upon their experience living with diabetes. DOC users, or peers, have diabetes themselves, or are family members or friends of someone who is affected by diabetes. It is difficult to ascertain how many people are using the DOC; however, it is global and appears to be growing. Notable are the registered users for TuDiabetes (35,000 members) and Type One Nation (23,000 members) and page views on Diabetes Daily (over 4 million from January – October 2014) (Diabetes Hands Foundation, 2014b; Juvenile Diabetes Research Foundation, 2014; G. Vieira, personal communication, November 3, 2014) at the writing of this article.

There is a network of websites that make up the DOC, which may include diabetes-specific and general social media sites, discussion boards, blogs, and online videos. Through sharing and/or linking, information provided on one DOC site may cross several social media platforms. Some DOC sites are moderated

by employed or volunteer peers (i.e., TuDiabetes, Reality Check) and medical advice, inappropriate comments or participants are removed (Gilbert, Dodson, Gill, & McKenzie, 2012). Other DOC sites are embedded within professional organizations (American Diabetes Association, 2013; Juvenile Diabetes Research Foundation, 2014). While there are no healthcare professional recommendations for DOC use and monitoring, several DOC sites are supported by healthcare providers who sit on their advisory boards or boards of directors (Diabetes Community Advocacy Foundation, 2014a; Diabetes Hands Foundation, 2014a).

The DOC is more than an online community and DOC users are increasingly engaged in activities other than asynchronous forums. Live chats where peers within the DOC facilitate programs that allow DOC users to participate in meaningful discussions on specific topics at a designated time are increasingly common and popular with DOC users. Examples include #DMSA Tweetchats or DSMA Live podcast radio programs. DOC users are initiating campaigns to improve diabetes awareness, such as Blue Fridays (Diabetes Community Advocacy Foundation, 2014b), and to validate and encourage others with diabetes, such as the You Can Do This Project (2014). Walk with D (P4DC, 2013) was created by DOC users to address diabetes related stigma by increasing the visibility of real life with diabetes. DOC users are also uniting in effort to create change that improves the lives of individuals living with diabetes; one example is having DOC representation at professional meetings (American Academy of Clinical Endocrinologists, 2014). Finally, DOC users are working

together to create products that improve their quality of life, such as NightScout, an open source “do it yourself” cloud-based continuous glucose monitoring project allowing users and other individuals to visualize fluctuations in blood sugar levels (The Nightscout Project, 2014).

The prevalence of diabetes is increasing among baby boomers (King, Matheson, Chirina, Shankar, & Broman-Fulks, 2013; Martin, Freedman, Schoeni, & Andreski, 2009). With the rate of diabetes diagnosis increasing with age, and the progressive nature of diabetes, primary and secondary prevention approaches are key to affecting the health of the baby boomer generation. It is suggested that e-health can augment secondary prevention (Renahy, Parizot, & Chauvin, 2008) by providing information needed to improve diabetes knowledge and management . While Internet use may differ among generations, there are few differences in online health information seeking behaviors (Fox, 2011). Baby boomers are rapidly adapting social networking (Zickuhr, 2010) and diabetes management tools that are able to complement care among baby boomers, such as the Internet, need further exploration.

Despite the growing reach of the DOC, limited research has been conducted as it relates to the DOC and its users within the nonhealthcare provider moderated, nontrained peer context. In addition, there is lack of research indicating how online health community users will use social media as they age forward. The purpose of this study was three-fold: 1) to describe why baby boomer DOC users participated in the DOC, 2) to describe how DOC users

interacted with their healthcare providers, and 3) to describe how baby boomers anticipated they would continue using the DOC as they aged.

Methods

Sample and Recruitment

This research summarizes a descriptive component of a larger study (see Chapter 4). The University of Utah Institutional Review Board granted approval for this research. The study was also approved by the administration team of each of the diabetes-specific social media sites in which participants were recruited. A 129-question online survey was posted to two diabetes-specific and two general social media sites that are a part of the DOC, to recruit adult DOC users who had diabetes and could read English.

A total of 183 participants completed the online survey after omitting caregivers for individuals with diabetes and minors. Upon completion of the online survey, participants who were baby boomers (born between 1946-1964) were invited to participate in qualitative arm of the study. Interested participants provided the author with personal information in order to be contacted about the interview. Potential participants were provided with written information about this study and a telephone interview was scheduled. At the beginning of the call, the interviewer reviewed the study and stated that the interview would be recorded; those willing to participate gave verbal informed consent. Participants were informed that a $20 donation would be given to the Diabetes Hands Foundation for their participation in this research.

Interview

A semistructured interview guide (see Table 5.1) was created through a review of literature and input by the research team. The goals of the interview were to obtain information about 1) why participants used the DOC (defined as any website that participants used to communicate with other individuals with diabetes for the purpose of information exchange), 2) how participants interacted with their healthcare providers for diabetes care, and 3) how participants anticipated use of the DOC as they aged. Questions related to the patient's demographics, diabetes diagnosis and treatment were also asked. All interviews were audio-recorded. Participants were informed that they did not have to answer any question they did not feel comfortable answering and could end the interview at any time. The interview recordings were transcribed verbatim and transcripts were verified for accuracy.

Analysis

A content analysis was used to analyze the data. Qualitative content analysis uses a consistent set of codes to organize similar data (Morgan, 1993). The first three transcripts were read and re-read along with the interview guide to generate the initial coding template by one of the principal investigators. The codes were then systematically applied to all of the transcripts with an option for open coding to capture any additional codes that may have been missed with the initial development of the codebook (Morgan, 1993; Sandelowski, 2000). The

Table 5.1
Interview Guide Probes

1. How did you first come to find the diabetes online community?
2. What diabetes online community sites are you using?
3. How do you typically seek help to manage your diabetes?
4. Where do you look most often for help about diabetes information?
5. Tell me about your experiences with your healthcare providers.
6. Tell me about your experiences using health oriented websites that are not social networking sites, discussion boards, or blogs.
7. Tell me about your experiences using the diabetes online community.
8. How do you decide if you believe or trust the health information you receive from your healthcare provider, health oriented websites, and the diabetes online community?
9. How do you use the information you receive from your healthcare provider, health oriented websites, and the diabetes online community?
10. How do you see the Internet playing a role in your healthcare over the next 20 years?
11. How will the DOC impact you as you age?
12. How is your experience using the diabetes online community different from people who have never accessed the diabetes online community?
13. What can you get from the DOC that you cannot get from your healthcare provider?

data were then retextualized to develop corresponding themes (Tesch, 1990). To establish credibility and auditability of the coding, the coded data of the first three transcripts were reviewed by dissertation committee members Drs. Linda Edelman and Erin Rothwell prior to the analysis of the remaining transcripts.

Results

Out of 76 baby boomers who participated in the online survey (see Chapter 4), 22 agreed to be contacted for an interview, a 29% response rate. Reasons for not participating were not collected as this was a second component of an online survey. Interviews lasted an average of 76 minutes. Two interviewed

participants were living outside of the United States and not included in this analysis. Therefore, 20 baby boomer DOC user interviews were analyzed. Average age of participants was 56 years (range 46-64 years, *SD* 5) and the average duration of time living with diabetes was 25 years (range 5-52 years, *SD* 15.2). Participants were predominantly type 1. Other demographic information for participants can be found in Table 5.2.

The content analysis focused on why participants used the DOC, how participants interacted with their healthcare providers for diabetes care, and how participants anticipated they would use the DOC as they aged. Six themes were identified: 1) wisdom from experience, 2) high desire for information to improve self-care, 3) emotional support, 4) belonging to a community, 5) validation of information, and 6) cause for concern.

Wisdom from Experience

All participants reported that they would continue using the DOC as they aged forward. Most participants stated that they would have more time on their hands to participate in the DOC as they became older, although a minority reported they thought that they might use the DOC less because they couldn't anticipate the challenges they would be dealing with as they got older, and how those challenges might impact their ability to use the DOC. Overall, participants felt that the DOC would become more important to them over time, noting that they would *grow grey together* with other DOC users. One participant noted, *I know there's always somebody—now, I know that there's always somebody out*

Table 5.2
Demographics for Participants

	n(%)
Gender	
Male	9(45)
Female	11(55)
Education Level	
Some College	4(20)
Associates Degree	2(10)
Bachelor's Degree	9(45)
Graduate or Professional Degree	5(25)
Race	
White	19(95)
Black or African American	1(5)
Geographic Location within the United States	
Northeast	5(25)
Midwest	2(10)
South	10(50)
West	3(15)
Living Setting	
Rural	5(25)
Suburban	11(55)
Urban	4(20)
Diabetes Type	
Type 1	12(60)
Type 2	4(20)
Latent Autoimmune Diabetes of Adulthood (LADA)	4(20)
Technology Use	
Using an insulin pump	12(60)
Using a continuous glucose monitor	11(55)
Most recent A1C reported to be	
5.9% or less	7(35)
6.0-6.9%	4(20)
7.0-7.9%	7(35)
8.0-8.9%	2(10)

Note. N=20

there who may have the same experience as me, a better experience even. Just knowing that there are people out there that are willing to talk over the next 20 years that are open to being contacted (Participant 18, F, 50y).

Several participants reported respect for “diabetes elders” and viewed DOC users who were living well with diabetes for several decades as role models for successful diabetes management. Participants commented that the successes of these diabetes elders were being used to benchmark their own diabetes management. One participant noted, *I'm 62, in the next 20 years I'm going to be falling apart. I expect to get a lot of help from the DOC on exactly that kind of thing. We have elders who have been living with diabetes 50 plus years* (Participant 10, F, 62y). Another participant noted, *I pay particular attention to my diabetic elders. Finding someone with 44 years or more experience is not exactly easy, but when I run into someone who does, if it makes sense, I will listen to where they point* (Participant 12, M, 46y). Experiences from diabetes elders were weighted as having more credibility than DOC users with less diabetes experience.

Participants reported they could learn diabetes and aging related complications to anticipate and avoid. One participant noted, *I’ve been reading about elderly people with diabetes and how with the cognitive changes you may not be as able to do the problem solving. So it makes me realize that one day, I might not be able to use the insulin pump. So it helps me think ahead and prepare* (Participant 14, F, 56y). Further, diabetes elders were looked to for

recommendations in managing aging related issues, such as menopause and Medicare coverage.

Several participants reported that they hoped to be in the respected position of “diabetes elder” as they aged, providing experiential information on how to live well with diabetes to those with less diabetes experience. Representative quotes include:

> There are a couple of people on the DOC that are about 65 years with diabetes. I like to read what they say. They are smart enough to say that they don’t have all the answers either. I would like to, as I do now, continue to say what my experience has been; good, bad, or indifferent (Participant 7, M, 57y).

> I hope some of my experiences that I share have purpose, are helpful and positive to others. I certainly know that those who have been older than me, that have had diabetes longer than me, have been positive impacts for me (Participant 4, F, 52y).

High Desire for Information to Improve Self-Care

Participants actively sought knowledge about diabetes management and viewed the DOC as a tool that allowed them to improve self-management of their diabetes. The exchange of peer knowledge found within the DOC increased participant confidence to take more responsibility for their health. One participant noted, *I think that I am a lot more confident in the choices I am making (*Participant 8, M, 55y*)* while another participant noted, *I have a broader and deeper knowledge about how to take care of myself* (Participant 10, F, 62y).

Participants stated they gained more comprehensive knowledge of diabetes through the DOC including learning about diabetes in general, but also new developments in diabetes treatments and additional strategies for

management of day-to-day situations. Examples included blood glucose management during exercise and travel, and trouble-shooting diabetes-related devices. This information was commonly communicated through an individual describing a personal experience and others comparing and contrasting these individual experiences. Representative quotes included:

> One thing about having all these different voices, is you see all these different perspectives. That does give you a much more in-depth knowledge of diabetes than what you read in the latest magazine, hearing a five-second sound bite, or the information from your primary [care provider] (Participant 3, F, 56y).

> You go to the doctor and you ask a question and you get one answer. You can either like it or lump it. You go on the Internet and ask a question, you get all these answers. You get to sift through them. (Participant 1, M, 59y).

The DOC also fostered communication with healthcare providers as participants stated they were encouraged to ask questions that pertained to their diabetes. One representative quote included:

> [The DOC] makes me smarter. I can't imagine anybody with some condition or disease not using an online community to seek out information. If you think about it, being online gives you the power to ask the doctor a question. You don't go in blind and just taking whatever he says for granted. When he recommends something you can say, "well, what about this? I read this." (Participant 15, M, 48y).

Participants reported the DOC was an adjunct to enhance diabetes knowledge and support between scheduled visits with their healthcare provider, not in lieu of seeing their healthcare provider. Healthcare providers were identified as a resource for medical advice, regarding the overall scope of one's health and to help with acute concerns. In contrast, the DOC was viewed as a resource for advice in dealing with day-to-day challenges and up to date information. Further, easily accessible information and support could be retrieved

from the DOC anytime of the day. Finally, the DOC was stated as a consistent source of diabetes information when the healthcare system had difficulties with continuity of care. Examples for continuity of care issues included high turnover among healthcare providers or difficulty getting an appointment. One participant noted, *It's ridiculously hard to get in to see the doctors in my community. So if it's something that I was really concerned about, we have urgent care, but I would probably tend to go to the online community to see if somebody had any ideas* (Participant 16, F, 57y). The DOC was also viewed as a resource to complement knowledge when questions seemed too insignificant to ask a healthcare provider. One participant noted, *You can't go running to the doctor every week. I'm in a situation where I go in every 6 months, in between I'm using that site, other sites, to help me make my decisions* (Participant 9, M, 64y).

Even when participants did not have difficulties accessing healthcare, the length of time they spent with healthcare providers was limited and the DOC was considered to be a way to receive additional information and education. Illustrative comments included:

> …because not only as a diabetic but as a diabetic educator, people need ongoing support and even to be an effective diabetes educator, I would need to see my patient's much more regularly than that time would allow. Social media can actually fill that gap (Participant 14, F, 56y).

> It's one of the things, I enjoy about the online community, being able to have the information. To not have to rely on my healthcare providers to tell me, you know, if they have time. I get to learn a lot of things that they don't have time to share on 15-30 minute meetings. It's a great tool. I'm not sure that people need to doctor themselves based on it, but it certainly is a good supplement (Participant 1, M, 59y).

Emotional Support

The majority of participants stated their healthcare providers were effective with the management of their healthcare overall. However, participants noted that their healthcare providers could not relate to all of the experiences of actually having diabetes. One participant stated, *My endocrinologist doesn't have diabetes, I think he gets it as much as he can, but he does not know the day-to-day challenges that it presents* (Participant 14, F, 56y). Participants also reported comfort in knowing that the struggle for blood glucose control was shared with other DOC members, and that there wasn't one single solution that fixed everything. The DOC provided mutual support and understanding in a way that healthcare providers, family members, and friends could not. Representative quotes include:

> It's not about getting an answer that you would fill in the blank on a test. Our lives aren't like that, but at least, if you're online with somebody and you see six different answers and somebody says, "It works like this…" and somebody says, "It worked like that for me." Then even if my answer isn't even one of the above, I feel better. I don't feel like I'm crazy because I don't have the one answer (Participant 3, F, 56y).

> My endocrinologist and certified diabetes educator are there for the 20 or 45 minutes. My appointment is to go over the most important medical things that I need to know. They're supportive and they do allow me to call them both…. When you want social support, you don't go to the medical professionals for social support. You go to your social circle of diabetes for that (Participant 19, F, 60y).

> I'm surrounded by people who don't get it, my personal circle, social circle, family circle. They don't get it. They have no idea. They see it, but they don't get it. It's nice to hear and see the supportive comments, even if they are not directed to me, to know that other people are dealing with this stuff (Participant 19, F, 60y).

Belonging to a Community

Through a shared interest in diabetes, participants described camaraderie within the DOC. Often participants had developed close enough relationships with other DOC users that they were considered *really good friends* or j*ust like family*. One participant noted, *the friendships that are developed on there are really enticing and it feels like you want to be part of this great club* (Participant 16, F, 57y). Several participants had already, or reported a desire to carry out their virtual friendship into the real world by meeting face-to-face. One participant noted, *people are very open hearted at the website, so when you meet people at these meet-ups, it's like you've known them forever. They're just wonderful* (Participant 10, F, 62y).

Participants participated in the DOC because it provided them with a sense of belonging. There was a give and take process, reinforcing solidarity among DOC users. When participants initially found the DOC, they reported it was to seek answers to their diabetes-related questions. However, several participants stated that they continued to participate with the DOC despite reaching a saturation point in their learning. One of the reasons participants reported they continued to stay engaged was because they wanted to give back to the DOC by helping others in order to help themselves. One participant noted,

> I guess I sort of think about Alcoholics Anonymous when they are talking about sharing the experience, strength and hope to try and help other people in order to help yourself. I think that's very true, that works on the diabetes websites too (Participant 7, M, 57y).

Participants reported that they gave back to the DOC because they had *been there*, with regard to a negative physical or emotional experience, or had

missed out on knowledge, support, or tips related to diabetes management. One participant noted, *It's empowering when you can give information to somebody who gets lost or when you can get information from somebody who has been there* (Participant 6, F, 51y). Another participant noted, *I see a lot of people, they come online and they have just been diagnosed and in a month or two they are pros, they're 10 years ahead of where I was* (Participant 1, M, 59y).

Another way participants reported they gave back to the DOC was through several types of advocacy. One type of advocacy included sharing information about the DOC with non-DOC users. Some participants gave information on DOC websites to friends, neighbors, and even strangers with diabetes. Other participants took DOC brochures to their healthcare providers in hopes that they landed into the hands of patients with diabetes. Some participants handed out DOC brochures to attendees at local in-person diabetes meet-up groups. One participant made sure DOC information was accessible at her local library while another participant included information about the DOC in a play she was producing about diabetes. One participant noted, *I'd like the world to know, the diabetes world to know, that there is something out there that can help them. I'm going to introduce my community to the diabetes online community because I think its important* (Participant 16, F, 57y). In addition, other participants advocated for the DOC in more formal ways, such as being a member of diabetes-related advocacy organizations.

Validation of Information

Participants described the importance of distinguishing good information from bad information. Participants reported distrust in statements claiming to reverse or cure diabetes. The majority of participants stated they would respectfully challenge misinformation to maintain community integrity and so other DOC users would not be harmed. Overall participants stated they were leery of anyone trying to sell them anything, such as a fad diet or supplements, and often times avoided clicking any ads unless it related to a diabetes related device (i.e., glucometer, insulin pump) they were interested in learning more about. Most participants stated that the DOC sites they frequented did not allow untrustworthy ads on the site. Some participants were aware of certain DOC users who traded goods (i.e., products, reimbursement for attending a conference) in exchange for blog posts and stated they were discerning when reading those.

Information found on the DOC was not taken at *face value*. Participants understood there was some risk in applying information they found on the web and that it was their responsibility to decipher what was relevant to them and their diabetes. One participant noted, *there's a lot of information out there, some of its good, some of its terrible, some of it doesn't apply, but that's incumbent on me to weed through it and figure out* (Participant 5, M, 52y). Participants described five different approaches in which they processed information found on the DOC. First, they went with their gut feeling. Participants would determine if the information passed the *smell test*, made reasonable sense to them, and

whether or not they felt it would be helpful to them. Second, there was consensus in numbers. Participants tended to believe information corroborated by several DOC users as opposed to just one or a few. Third, fact checking occurred before acting. Participants would cross reference information found on the DOC by trying to find similar information on other DOC sites, general health sites they trusted (i.e., NIH, CDC, Mayo Clinics), professional journals, and/or by talking with their healthcare provider. One participant noted,

> If somebody mentions something, I get confirmation from other places. I wouldn't make a change if I hadn't gotten confirmation from someone or somewhere else because you never know. They don't know who I am, I don't know who they are. So I always try to confirm it before I make any changes on my own (Participant 2, F, 52y).

In summary, most of the participants were interested in experiences, not medical advice. Participants valued and were more likely to trust information if DOC users expressed that their diabetes may vary from another's, and shouldn't be taken as gospel. One participant noted, *The people who I trust the most are the ones who are living it, who say, "This works for me. You might want to try it, but remember, I'm not a doctor and I'm not you." You have to be careful. I don't trust the people who say, "Do this, it works"* (Participant 16, F, 57y). Finally, when someone did decide to try something they learned from the DOC that would affect their blood glucose levels, they tested their blood glucose levels more often and/or used a continuous glucose monitor to evaluate how the change affected their glucose control.

Cause for Concern

Many participants did report concerns related to the DOC and were discouraged by individuals who used the DOC to disclose overly emotional or nondiabetes related issues, and stated they participated in the DOC to help create positive experiences. One participant noted, *I have tried to make [DOC use] a more positive experience and I've realized a lot of people go online when they want to vent. I have to be in the right kind of mood to read that. If I get online and everybody's venting, I get off real quick* (Participant 20, F, 59y). Other participants stated they became frustrated when other DOC users complained or made excuses for poor management of diabetes. Some participants reported that they could not relate to the negative comments expressed by some DOC users. One participant stated, *There were so many people that were so negative and I never felt that way. I could not identify with that. There are things that I can't identify with that go on in the community* (Participant 1, M, 59y).

Participants stated concerns when DOC users posted desperate messages about acute health issues. Participants reported the DOC was an inappropriate place to resolve urgent health issues. One participant noted,

> There was one girl online the other day, "I've been feeling sick for several days. I think it's DKA. Should I call my doctor?" "Yes! Get off Facebook and call your doctor." [Did people encourage her to do that?] Yeah. There were a few that did. Other people just kind of commiserated. That was kind of scary" (Participant 3, F, 56y).

Bullying, cliques and judgmental and rude behaviors were other concerns voiced by participants. One particular issue raised by multiple participants was the disagreement between individuals with type 1 and type 2 diabetes. These

disagreements, such as the cause of type 2 diabetes solely from obesity, were described as misconceptions. Participants avoided DOC sites where negative discussions occurred. One participant noted, *A few years ago I participated [in the DOC] but some of them have a lot of aggressive people, a lot of nonsense, people being rude to each other, no control. I stay away from that. I quit participating for a year and now I'm signed back up again* (Participant 1, M, 59y).

Discussion

This is the first research study to describe why baby boomers engage in the DOC and the perceived advantages related to its use. Overall, baby boomer DOC users highly valued the ability to crowdsource diabetes related information and reciprocate support among peers. Through increased knowledge and support, participants felt empowered to take better care of themselves today and as they aged. What was gained from the DOC was clearly different and complementary to the information and support they receive from their healthcare providers.

Baby boomer participants viewed other DOC users as experts in living with diabetes who shared tacit knowledge. Participants were not engaging with the DOC to go against medical advice. Instead, the DOC filled a gap in the current healthcare system, supplemented knowledge, provided mutual support and understanding, empowered participants to have more confidence in diabetes self-care behaviors and proactively communicate with their healthcare providers. Other research supports these findings. Shaffer-Hudkins, Johnson, Melton, and

Wingert (2014) found that DOC users were motivated to be healthy and had more confidence in their diabetes management. Further, participation in health-related online communities is associated with empowerment (Mo & Coulson, 2014; Oh & Lee, 2012; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009; van Uden-Kraan et al., 2008) and improved communication with healthcare providers (Holbrey & Coulson, 2013; Maloney-Krichmar & Preece, 2005; Mo & Coulson, 2014; Oh & Lee, 2012). Healthcare providers are a single resource within large network of health information sources (Fox & Duggan, 2013a; Vassilev et al., 2013); peers within the DOC make up several nodes or connection points to health information who can fill the gap where healthcare providers fall short (Fox, 2013). In this study, healthcare providers were sought when participants were in need of medical advice while DOC users were relied upon for experiential advice related to day-to-day issues.

DOC users provided validation through mutual support and understanding that was distinctly different from what was available to them offline. Individuals with chronic conditions are more likely to turn to online support when they lack real world support (Cummings, Sproull, & Kiesler, 2002; Turner, Grube, & Meyers, 2001). In this study, the relationships forged with total strangers resulted in strong connections and friendships, even to the point of meeting in-person, increasing alloy social capital. Alloy social capital is the enhancement of relationships through meeting both online and offline (Sander, 2005). Social connectedness is a strong predictor of altruism (Putnam, 2001), and has been identified in other health-related social media research (Chung, 2013; van Uden-

Kraan et al., 2008). Even after participants had received answers to all of their questions, participants continued to engage with the DOC for the purpose of helping other DOC users who may benefit from participant knowledge and experience. In addition, participants advocated for DOC on and offline. This is perhaps related to altruism, but may also be related to interest in continual improvement of the DOC, and DOC related research, based upon increasing the volume of participants. Research has indicated that communities can undergo a process of synergy in which healing and empowerment occurs, strengthening both the individual and community at large (Katz & Murphy-Shigematsu, 2012). These results suggest that a synergistic process occurs within the DOC, resulting in group cohesion, pursuit of improved diabetes knowledge and support, and positive gain through participation. Further research is needed to explore the dynamics of synergy, healing, and empowerment within the DOC.

Baby boomer DOC users described a process in which they would examine DOC postings in order to identify credible information that was applicable to their clinical situation. Misinformation within the online health context is a concern shared by some healthcare providers (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006; Moick & Terlutter, 2012). In attempts to find accurate information, participants actively fact checked with sources they trusted, including their healthcare providers. Similar behavior has been identified by Pew Research Center's American Life Project (Fox & Duggan, 2013b). Participants also understood when information would be useful to them and when it did not pertain to their clinical situation, as has been noted in other research

(Armstrong & Powell, 2009). In this study, DOC users used an unofficial self-policing model in which they corrected each other when misinformation was provided; much in the same was as moderated DOCs handle misinformation (Armstrong, Koteyko, & Powell, 2012; Gilbert et al., 2012). Several DOC users provided examples of DOC dialogues in which going against FDA and manufacturer recommendations for insulin pump and continuous glucose monitor sites had been discussed, although with an international base of DOC users, the FDA may not pertain to all individuals. The degree to which participants will correct misinformation in a peer-led, nonmoderated DOC is unknown.

Several participants mentioned cyber-bullying or rude behavior, which is poorly understood in the peer health context. The online disinhibition effect, as described by Suler (2004), may result in DOC users feeling less apprehensive about negatively acting out due to anonymity. One participant was not the victim of bullying, but was aware of rude behavior and temporarily left the DOC because of it. In nonhealth-related online communities, harassment or bullying has been described as one of several reasons why someone may stop or decrease their online community use (Brandtzæg & Heim, 2008). Cyber-bullying is not well documented among adult cohorts. However, among adolescents, cyber-bullying is associated with mental health problems (Bannink, Broeren, van de Looij-Jansen, de Waart, & Raat, 2014) such as substance abuse, violent behavior, unsafe sexual behavior, and suicidal behavior (Litwiller & Brausch, 2013). Healthcare providers should be aware of cyber-bullying or harassment from participating in the DOC, and how it might impact mental health. Baby

boomer participants did not report concerns with health privacy, such as how sharing information regarding personal habits or psychological conditions, might affect their ability to obtain health insurance or get a job, as has been described elsewhere (Abril & Cava, 2007; Househ, Borycki, & Kushniruk, 2014).

Baby boomers are the first generation to transition into older adulthood with Internet skills; because of this, the Internet will play a much greater role in the health of baby boomers than previous generations. In fact, Chung (2013) found that over half of the participants in online health communities are comprised of individuals aged 50 or older. Internet use has been found to be associated with higher satisfaction in health, well-being, and sense of community in baby boomers and older adults (Sum, Mathews, Pourghasem, & Hughes, 2009). In this study, baby boomers were embracing social media and how the DOC could support them now and as they aged. Lieberman and colleagues (2005) found that homogenous online groups, based on similarities in age and time since diagnosis, provide more benefit than heterogeneous groups. In this study, participants found value from individuals who were homogenous with relationship to gender, use of specific diabetes devices or medications, and shared experiences. Further, optimal heterophily, defined as when individuals have contact with others who have similar interests and a shared perspective (i.e., diabetes) with one distinct difference, one of the individuals has more experience (Walther et al., 2010), was identified. DOC users were valued for more experiential years with diabetes, with and without regard for chronological years. DOC users with many decades of diabetes experience have overcome

many treatment obstacles, such as lack of home glucose monitoring or less physiologic insulin regimens, and have persevered into older age. Learning from individuals who had survived the odds against them proved to be valuable. Individuals also appreciated information from a chronological standpoint as it related to the health-related changes they could anticipate as they became older, such as changing insurance coverage to Medicare or insulin management changes due to age-related cognitive changes. While years since diabetes diagnosis and chronological years were both valued, more weight was placed on actual years of experience living with diabetes. This meant that “diabetes elder” would not always be categorized as an older adult in today’s society. For example, someone diagnosed with diabetes at age 2 could have 48 years of diabetes experience before reaching age 50. Overall, the role of diabetes elder was well respected and a position participants hoped to one day attain in order to help younger counterparts.

Healthcare providers should anticipate changes in how baby boomers will seek information for health compared to previous generations. It is well established that healthcare providers are needed to support the aging population (Olshansky, Goldman, Zheng, & Rowe, 2009; Ricketts, 2011) and these healthcare providers should understand how the DOC can support the health of their patients with diabetes. As identified in this study, DOC users continued to see their healthcare providers for medical advice. Healthcare providers may find the DOC complements their practice, filling a gap as it relates to day-to-day tacit

knowledge and support, allowing for a more comprehensive approach to diabetes care.

The digital divide will become less significant as baby boomers age. Baby boomers already using the Internet and the DOC will not require the same training that many older adults require to use the Internet, although training related to platform updates or new developments may be necessary. Developers of DOC sites may consider developing trainings to support updates and changes for their aging users. Vision changes can be an age or diabetes related complication. As individuals age, larger font may be necessary, although computers offer the ability to zoom in, increasing the text size, when viewing websites. New technologies also offer voice recognition support for those with low vision. The fast-paced nature of some DOC programs (i.e., Tweetchats on Twitter) may be difficult for some aging adults to comprehend or keep up with and asynchronous or slower-paced DOC sites may be preferred. Finally, age related cognitive or physical changes may affect the ability of baby boomers to continue using the DOC. Diabetes elders that are no longer able to participate in the DOC may leave other DOC users they have developed relationships with sad, frustrated, or worried. Research, specifically longitudinal studies, is needed to better understand changes in participation with online health communities as it relates to aging.

Limitations

There are several limitations. First, this study was conducted using telephone interviews with baby boomers who self-selected to participate in the study and may not reflect the views of the all baby boomers using the DOC, or DOC users who cannot be categorized as a baby boomer. Further, this sample was predominantly type 1 who had diabetes for a longer period of time, and not the prototype newly diagnosed adult with type 2 diabetes which will predominate in the boomer generation. Second, all participants were from the United States and therefore data cannot be generalized to DOC users in other countries. Other research methods, such as analyzing discussions within the DOC, should be employed to triangulate data. Finally, this study is descriptive in nature; further research should identify how knowledge and support attained from the DOC may impact health outcomes.

Conclusion

The findings in this study suggest that DOC can be conceptualized as providing peer health and support for baby boomers as they age. DOC users highly value the DOC and regard their participation as a vehicle to increase knowledge to improve self-care and reciprocate emotional support with others who have shared experiences in diabetes management. Participants respected diabetes elders and aspired to become a diabetes elder themselves, anticipating continued use of the DOC aging forward. DOC use was complementary to regular medical provider visits, filling a gap that provided tacit knowledge that is

not readily available offline. To strengthen individuals and the community at large, DOC users actively helped others within the community and sought out new users. DOC users methodically processed information to determine credibility and relevance to their own situation. While several benefits were reported, cyber-bullying and rude behaviors were worrisome and DOC users sought ways to avoid unwanted encounters. Therefore, healthcare providers should become familiar with the DOC and consider it an important source of information for their aging patients. This study contributes to the knowledge base of multiple site DOC use in the non-healthcare provider moderated, nontrained peer context.

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CHAPTER 6

CREDIBILITY OF INFORMATION, HELP, AND HARM WITHIN THE DIABETES ONLINE COMMUNITY

Abstract

In recent years there has been a rise in adults searching for health information online. There are concerns regarding the credibility of online health information, and how this may relate to being helped or harmed. Individuals who engage in the diabetes online community (DOC) are able to interact with peers who have the same medical condition, diabetes. Apomediation Theory suggests peers, or apomediaries, can guide individuals to credible information. Baby boomers, the first generation to age with the option of engaging in online peer health for disease management, are important to study as their Internet use relates to credibility, help, and harm of online health information. The purpose of this study was to describe the perceived source credibility of information shared by the DOC; examine differences in perceptions of DOC source credibility, help, and harm among baby boomers and younger adult counterparts; and describe if baby boomer DOC users viewed the DOC as an apomediated environment with regard to the credibility of its information.

A concurrent mixed method approach was taken and included a cross-sectional survey conducted among adult DOC users using an online survey posted to several DOC social media sites. Additionally, a baby boomer subset of online survey participants were interviewed, interview transcripts were analyzed using directive content analysis, using the credibility issues identified in Apomediation Theory as a framework.

DOC users perceived the health information on the DOC to be credible and employed a process to evaluate credibility described in Apomediation Theory. Those using the DOC reported being helped by the DOC with practically no harm reported, suggesting the DOC is beneficial with low risk. The participants' perceptions of the credibility of DOC information were associated with high diabetes self-care and high social capital, both indicators of health in individuals with diabetes. Finally, there were no differences in credibility, help, or harm scores among baby boomers and younger adults. Future research as it relates to being helped or harmed by the DOC is warranted.

Introduction

An increasing number of individuals are searching for health information online. Individuals with chronic conditions are going online to learn about the personal health experience of peers with the same condition (Fox & Duggan, 2013). Online health information is vast, making it more difficult to discern what is credible and reliable. In fact, credibility of online health information is an ongoing concern for the healthcare community (Ahmad, Hudak, Bercovitz, Hollenberg, &

Levinson, 2006; Moick & Terlutter, 2012) and research is conflicting regarding the quality of online health information (Kavathe, 2009; Percell, Wilson & Delamothe, 2002). While health consumers also have concerns about misinformation, there is evidence that Internet users know how to discern good from bad information (Fox, 2008). It is important for online health information seekers, such as those engaging in the DOC, to be able to identify credible sources of information.

Diabetes Online Community

Individuals with diabetes are turning to the DOC to engage in peer health. The DOC is a grassroots community developed by people affected by diabetes with the purpose of sharing diabetes knowledge and support based upon their experience living with diabetes. DOC users, or peers, have diabetes themselves, or are family members or friends of someone who is affected by diabetes. A collection of individual voices, experiences, and opinions make up the DOC.

DOC peer health may assist individuals better relate to health information; however, a number of concerns have been voiced about the credibility of information (i.e., source credibility) shared in various peer health platforms. First, the quality of information found within diabetes social media sites varies (Weitzman, Cole, Kaci, & Mandl, 2011) and may not provide necessary information to assist with medical decision making (Weymann, Härter, & Dirmaier, 2014). Second, not understanding the difference between credible information and misinformation could lead to serious consequences. However,

analysis of online diabetes discussion boards has indicated that misinformation has been found to be infrequent (Armstrong, Koteyko, & Powell, 2012; Greene, Choudhry, Kilabuk, & Shrank, 2011; Hoffman-Goetz, Donelle, & Thomson, 2009) and quickly corrected by peers when it does occur (Armstrong et al., 2012; Gilbert, Dodson, Gill, & McKenzie, 2012). Finally, some individuals may not be able to determine if online health information applies to their own clinical situation (Lo & Parham, 2010), although Armstrong and Powell (2009) found that individuals with type 1 diabetes do understand when online health information is applicable to them, and when it is not. It is important for DOC users to be able to ascertain the source credibility of information as they navigate peer health online health information in order to mitigate harm and maximize benefits.

Diabetes and Aging

The prevalence of diabetes and proportion of older adults with diabetes are simultaneously increasing. Baby boomers (born 1946-1964), who make up the vast growth of older adults, have a higher incidence of chronic conditions such as diabetes (King, Matheson, Chirina, Shankar, & Broman-Fulks, 2013; Martin, Freedman, Schoeni, & Andreski, 2009). With the oldest baby boomer turning 65 in 2011, the number of older adults with diabetes will overwhelm our current healthcare system. Baby boomers are the first generation to age using the Internet and Web 2.0 applications during their younger years. Web 2.0 applications have been viewed as helpful in providing primary and secondary prevention (Renahy, Parizot, & Chauvin, 2008). It will be important to determine

source credibility of Web 2.0 applications, websites that facilitate interactivity and co-creation of content by website visitors (Walther et al., 2010), such as the DOC, among baby boomers as this may inform online search behavior as they age.

Source Credibility

Source credibility is an important construct within interpersonal communication (McCroskey, 1966) and relates to perceptions of competence, trustworthiness, and goodwill/caring (McCroskey & Teven, 1999) of the information provided by peers. Emotional support has been associated with source credibility in online health communities (Campbell & Wright, 2002). Through the exchange of personal information and shared experiences, peers of an online health community may develop trust in one another. However, source credibility may be more difficult to ascertain in online environments due to reliance on text without the support of nonverbal cues and facial expressions (Campbell & Wright, 2002; Wright, 2000), although emoticons may positively enhance this. Source credibility is an important factor when determining credibility in online health information.

Health information is not credible without trust in the message and source. There are conflicting reports regarding the association between trusting online health information and social capital. In a national survey, social capital was not associated with online health information (Ye, 2010). However, the online health information in this study was not embedded within an online community. Putnam

(2000) suggested trust is one of many positive factors that can come from social capital found in social networks such as online health communities. Research indicated general social networking sites, such as Facebook, can facilitate social capital and trust (Ellison, Steinfield, & Lampe, 2007), although social capital is not commonly seen when connecting with strangers (Ellison, Steinfield, & Lampe, 2011), which may be more common within an online health community. Other research suggests online health community users are more likely to perceive community information as credible if they show a preference for weak ties (bridging social capital), or diverse points of view based on firsthand knowledge of a health issue (Wright & Rains, 2014).

Online Health Information Providing Help or Harm

It is unclear if online health information seeking is helpful or harmful to consumers. The Pew Internet and Life Project found that 30% of US adults report they or someone they know had been helped by following the advice or health information found on the online and only 3% reported being harmed (Fox, 2011). In contrast, physicians are concerned that patients seeking online health information could stress the physician-patient relationship if patients bring up inaccurate or irrelevant information and demand extra time or testing (Murray et al., 2003). Safety is a concern as well. For example, inaccurate health-related online material with the potential to result in harm could be targeted to consumers, such as cigarettes, drugs, and medical devices (Lau, Gabarron, Fernandez-Luque, & Armayones, 2012; Miller, 2013); public displays of

unhealthy behaviors, such as self-harm or hurting others; tainted public health messages; psychological impact from accessing offensive or biased content; and distortion of policy or research funding agendas (Lau et al., 2012). Therefore it is be important to evaluate how DOC users perceive information shared by the DOC as it relates to being helpful or harmful.

Apomediation Theory

One way that individuals establish credibility of online health information is through the guidance of peers as suggested in Apomediation Theory. Apomediation theory proposes individuals can bypass the traditional hierarchical medical system and, through a filtering process, collaborate with experienced peers who guide them towards credible and relevant information. There are three ways in which credible health information can be obtained: 1) intermediation, 2) disintermediation, and 3) apomediation (see Figure 1.1). Traditionally healthcare providers have been seen as experts or intermediaries of credible and relevant health information. Information on trusted websites approved by experts, such as the Center for Disease Control, World Health Organization, and other professional organizations, can also be seen as intermediaries. In disintermediation, patients bypass their healthcare providers and seek online health information. Without guidance, patients are on their own to decipher what is credible on their own. Apomediation is the process in which individuals are guided to credible and reliable information through the collaboration of peers who have produced opinions based on experience. Apomediation is seen in Web 2.0

applications such as consumer ratings, blogs, wikis, social networking sites, and online health communities (Eysenbach, 2008b). The practice of intermediation, disintermediation, and apomediation is fluid and depends on patient preference and the nature of the medical condition (see Figure 1.2). As it relates to diabetes, individuals may be more reliant on their healthcare providers upon initial diagnosis. However, over time autonomy, knowledge, and self-efficacy are gained, allowing for transition to a disintermediated or apomediated approach. Intermediaries are contacted when credible information cannot be found through disintermediation or apomediation, or when an acute condition is present. Once intermediaries have provided the patient with adequate support, the patient may then move back to a disintermediated or apomediated approach (see Table 1.1) (Eysenbach, 2008b).

Little information is known about help, harm, and credibility of information on peer driven health websites, such as the DOC. The purpose of this study is three-fold: 1) to describe the perceived source credibility of DOC and diabetes healthcare provider team information, 2) to examine differences in perceptions of DOC source credibility, help, and harm among baby boomers and younger adult (born 1965-1980) counterparts, and 3) to describe if baby boomer DOC users view the DOC as an apomediated environment with regard to source credibility.

Methods

Study Design and Sample

A concurrent mixed method approach was taken to sequentially capture data with regard to perceived credibility of information provided by DOC users. First, a cross-sectional survey was conducted among adult DOC users using an online survey posted to several DOC social media sites. Second, a subset of baby boomer online survey participants were interviewed to determine how credibility of the information found within the DOC was established, and to determine if it was consistent with Apomediation Theory (Eysenbach, 2008b). The University of Utah Institutional Review Board approved this study. In addition, two diabetes-specific DOC administration teams in which the study was posted for recruitment purposes approved of this study.

DOC users who had a diagnosis of diabetes, could read English, and were at least 18 years or older were invited to participate in the online survey. Anyone born in 1945 or earlier, minors and caregivers for individuals who responded to the online survey were omitted from the analysis. After completing the online survey baby boomer participants were invited to participate in an in-depth telephone interview. Results as related to help, harm, and credibility of the DOC are reported here; other results from the parent study are reported elsewhere (Chapter 4-5).

Survey Development

A 129-question survey was developed as described in Chapter 3 and 4. Demographic information, health history, and web 2.0 application use were collected. Health history questions included the type of practice their main diabetes healthcare provider worked in and how frequently they saw a healthcare provider for diabetes. In addition, six scales were used to capture data regarding source credibility, DOC engagement, DOC intensity, social capital, health-related quality of life, and diabetes self-care.

DOC Intensity Scale

The DOC Intensity Scale is an 8-item tool adapted from the Facebook Intensity Scale (Ellison, Steinfield, & Lampe, 2007),which was created to measure how often and for how long individuals were engaging with Facebook in order to determine emotional connectedness to the site and how Facebook was integrated into daily activities (Cronbach's alpha = 0.83) (Ellison et al., 2007). The DOC Intensity Scale measures DOC usage, active engagement in the DOC, the number of DOC friends, hours spent on the DOC, and emotional connection to the DOC. The 5-point Likert DOC Intensity Scale is calculated by taking the mean of scores on all items in the scale, resulting in a continuous variable ranging from 0-5.

DOC Engagement

DOC engagement was measured by asking 5 dichotomous yes/no questions related to whether or not participants: shared clinical information, requested or provided clinical guidance or feedback, and received or provided emotional support. Findings from a qualitative analysis of types of posts from DOC users on Facebook informed the development of these questions (Greene et al., 2011). A DOC engagement score was obtained by summing the number of yes responses for the 5 variables. Scores ranged from 0 indicating low engagement to 5 indicating high engagement.

Internet Social Capital Scale

The Internet Social Capital Scale (ISCS) is designed to measure bonding and bridging social capital in both online and offline environments using a 5-point Likert scale to measure either broad Internet use or more specific Internet activities, such as DOC use (Williams, 2006). The original study using the scale reported a Cronbach's alpha of 0.90 for the online survey, which measured both broad and specific Internet use (Williams, 2006). For this study, the question on the bonding subscale, "If I needed an emergency loan of $500, I know someone on the online I can turn to" was changed to "If I needed an emergency loan of diabetes supplies, I know someone on the DOC I can turn to." Three additional questions from the ICSC bonding subscale that did not pertain to the study population were omitted with permission from the original scale designer (Williams, 2006). The adapted 7-item bonding social capital scale and 10-item

bridging social capital scale are scored by computing the mean scores; each domain score has a possible range of 0-5 with higher scores indicating higher levels of social capital.

Health-related Quality of Life

The SF-12v2 health survey, with a 4-week recall, was used to measure health-related quality of life (HRQOL). The SF-12v2 is the second version of the SF-12, originally developed in 1994 to measure health-related quality of life through physical and mental component summaries of 8 health domains of HRQOL (Ware, Kosinski, Turner-Bowker, & Gandek, 2002, 2007). Norm based scoring (Mean = 50, *SD*=10) was used for this analysis (Ware et al., 2007). When tested in the general population in the United States, the Cronbach's alpha ranged between 0.73 and 0.87, with the mean physical component summary being 0.89 and mental component summary being 0.86 (Ware et al., 2007).

Diabetes Self-Care Behaviors

The Self-Care Inventory was originally developed by La Greca and colleagues (1988) and later revised (Weinger, Butler, Welch, & La Greca, 2005) to measure diabetes self-care behaviors. The 15-item Likert scale Self-Care Inventory Revised measures diabetes self-care behaviors, accommodating for the natural variation in treatment plans for patients with type 1 or type 2 diabetes, and duration since diagnosis. The Self-Care Inventory Revised is scored between 0-100, a higher score indicating more self-care. The Cronbach's alpha

for the Self-Care Inventory Revised in a study including 3 datasets was 0.85 (Weinger et al., 2005).

Source Credibility

DOC and health provider source credibility was measured using a scale first developed in 1966 (McCroskey, 1966) and revised in 1999 (McCroskey & Teven, 1999). The revised scale includes 18 items which measuring three factors: competence, trustworthiness, and goodwill/caring (McCroskey & Teven, 1999). The Source Credibility scale has been used to measure credibility of online discussions (Adi, 2007; Ng & Detenber, 2005; Stam, 2010; Tan, Swee, Lim, Detenber, & Alsagoff, 2007) and healthcare providers (Paulsel, McCroskey, & Richmond, 2006; Paulsel, Richmond, McCroskey, & Cayanus, 2005). In the revised version, Cronbach's alpha scores range from .85 to .92 when looking at the factors separately, and .94 when scored as a single measure. The scale uses a 7-point semantic differential scale for items such as "informed/uninformed," "understanding/not understanding," and "honest/dishonest." We used the Source Credibility scale twice in this study: first to identify how participants rated the source credibility of the DOC, and second to identify how participants rated the source credibility of their diabetes healthcare team. The diabetes healthcare team included anyone who cared for the patient's diabetes. Possible scores ranged from 0-42.

Participants were asked two online survey question based on questions asked in the Pew Research Internet Project (2012) Health Survey. The first

asked if they or anyone they knew had been helped by following advice or health information found in the DOC. The second question was asked in the same fashion, with the focus being on harm. Responses included major help/harm, moderate help/harm, minor help/harm, no help/harm, or don't know.

Data Collection

Information about the online survey, with a link to participate in the survey, was posted to the author's profile page on a DOC site and then strategically shared by the researcher, opinion leaders, and DOC administrators to recruit participants. Once participants clicked on the link to take the online survey, they were sent to Research Electronic Data Capture (REDCap) Survey (Nashville, TN), a secure, web-based tool used to create and manage online surveys, where the online survey was maintained.

After completing the survey, those born between 1946-1964 (baby boomer generation) were invited to participate in the qualitative arm of the study exploring the process DOC users undertook to established if the information they found on the DOC was credible. Interested participants were contacted by email to schedule an interview. Participants who verbally consented to the interview underwent an in-depth phone interview conducted using a semistructured interview guide. Participants could cease the interview at any time. Interviews were then transcribed verbatim by either a transcription company or by the principal investigator. All interviews were audio recorded on a digital device. After all interviews were transcribed, the principal investigator checked for accuracy of

each transcript by listening to the interview and reading the transcript simultaneously.

Statistical Analysis

Descriptive statistics were used to analyze participant characteristics including gender, age, education level, income, insurance, country, and diabetes type. “Younger adults” were coded to include those from the Millennial and Gen X generations (born between 1980-1965). Correlations, univariate analyses, and t-tests examined the associations between DOC user characteristics, source credibility, social capital, and health indicators. Fisher’s least significant difference (LSD) procedure was used for post-hoc analysis for significant omnibus analysis of variance tests. Paired *t*-tests examined the differences in how participants rated each factor of source credibility as it related to the DOC and the diabetes healthcare team. Analyses were performed with SPSS version 22. Alpha was set at 0.05.

Qualitative Analysis

Using a qualitative approach, a directive content analysis was used to analyze the text. Directive content analysis utilizes a theoretical framework as a guide for initial codes (Hsieh & Shannon, 2005). The credibility issues identified in Apomediation Theory (Eysenbach, 2008b) provided the framework for the coding schema. The researcher read and re-read the interviews to become familiar with the data, indexed the codes according to the theory, created charts

to organize data within the thematic framework to allow for data synthesis, then interpreted the data (Lacey & Luff, 2001; Pope, Ziebland, & Mays, 2000; Ritchie & Spencer, 2002).

Results

Quantitative Results

Demographics

A total of 207 individuals completed the survey. After removing submissions provided by participants born 1945 or earlier, minors and caregivers, a total of 178 participants met criteria for this study: 43% were baby boomers and 57% were younger adults. Participants were more likely to be female, White, living in the United States, well educated and insured, and have type 1 diabetes (see Table 6.1).

Source Credibility of All Participants

Three factors of DOC source credibility − competence, caring/goodwill, and trustworthiness − were measured for all survey participants. The mean DOC competence score was 31.9 (*SD* = 6.5), the mean DOC caring/goodwill score was 31.9 (*SD* = 7.2), and the mean DOC trustworthiness score was 33.6 (*SD* 6.3). Each factor score had a possible range of 0-42. Cronbach's coefficient for the DOC source credibility scale were: DOC competency (α=.89), DOC caring/goodwill (α=.89), and DOC trustworthiness (α=.91).

Table 6.1
Demographic Variables of Baby Boomers Compared to Younger Adults

	Baby Boomers (*n*=76, 42.7%)	Younger Adults (*n*=102, 57.3%)	Total (*SD* or %) (*n*=178)	*p*-value
Age, mean (*SD*), range			43.8(13.2) 18-67	
Gender, No. (%)				.184[b]
Female	51(68)	77(77)	128(71.9)	
Male	24(32)	23(23)	47(26.4)	
Race, No. (%)				.646[b]
AI or AN[a]	0(0)	2(2)	2(1.1)	
Asian	1(1.3)	2(2)	3(1.7)	
African American	1(1.3)	1(1)	2(1.1)	
White	73(97.3)	96(95)	169(94.9)	
Country, No. (%)				.025[c]
United States	69(90.8)	78(77.2)	147(82.6)	
Not United States	7(9.2)	23(22.8)	30(16.9)	
Education, No. (%)				.698[b]
Some High School	0(0)	2(2)	2(1.1)	
High School Graduate	5(6.6)	5(5)	10(5.6)	
Some College	14(18.4)	13(12.9)	27(15.2)	
Associates Degree	9(11.8)	11(10.9)	20(11.2)	
Bachelor's Degree	25(32.9)	39(38.6)	64(36)	
Gradate/Professional Degree	23(30.3)	31(30.7)	54(30.3)	
Insurance, No (%)				.062[d]
Insured	73(97.3)	84(86.9)	157(82.6)	
Uninsured	2(2.7)	9(6.1)	11(16.9)	
Diabetes Type, No. (%)				.007[c]
Type 1	45(59.2)	82(80.4)	127(71.3)	
Type 2	18(23.7)	13(12.7)	31(17.4)	
LADA[b]	13(17.1)	7(6.9)	20(11.2)	

[a]American Indian or Alaskan Native
[b]Latent Autoimmune Diabetes of Adulthood
[c]Chi-Square
[d]Fisher's exact test

In all participants, the 3 DOC source credibility factor (competency, caring/goodwill, and trustworthiness) positively correlated with diabetes self-care, DOC intensity, and DOC engagement, and bonding and bridging social capital of all participants (see Table 6.2). Participants reported higher scores for all DOC source credibility factors in 12 of 13 examined DOC benefits (see Table 6.3). DOC competence scores were higher (p<.05) for individuals who had told their healthcare providers about their DOC use and were supported to continue doing so (M=34.3, SD=6.1) than those who weren't sure if their healthcare providers supported their DOC use because they hadn't told their healthcare providers about it (M=31, SD=6.6). Similarly, all participants reported higher DOC caring/goodwill scores if they had told their healthcare providers about their DOC use and their healthcare providers supported it (M=34.7, SD=5.4, p<.01) or weren't sure if their providers supported their DOC use even after they had reported it (M=34.2, SD=7.4, p<.05) when compared to those who had not told their healthcare providers about their DOC use at all (M=30.8, SD=7.4). DOC source credibility factor scores were not related to age, gender, diabetes type, diabetes duration, diabetes treatment, diabetes related complications, A1C, or health-related quality of life.

DOC and Healthcare Provider Source Credibility

The three factors of source credibility were also measured to determine the credibility of information coming from the participants' diabetes healthcare provider team. For all participants, the mean diabetes healthcare provider team

Table 6.2
Pearson's Product Correlations for DOC Source Credibility

	Diabetes Online Community		
	Competence	Caring/Goodwill	Trustworthiness
Diabetes Self-Care	.144	.158*	.169*
DOC Intensity	.364***	.465***	.322***
DOC Engagement	.196**	.285***	.215**
Bonding Social Capital	.368***	.504***	.412***
Bridging Social Capital	.369***	.484***	.380***
Physical HRQOL	-.002	.040	.060
Mental HRQOL	-.021	.014	.034

Note. *=p<.05, **=p<.01, ***=p<.001. N=178

Table 6.3
DOC Source Credibility Is Associated with DOC Benefits

DOC Benefit	DOC Competence			DOC Caring/Goodwill			DOC Trustworthiness		
	Mean	*SD*	*p*-value	Mean	*SD*	*p*-value	Mean	*SD*	*p*-value
Feel understood			.000			.000			.000
Yes	33	6.2		33.4	6.1		34.7	5.7	
No	27.5	6.8		25.8	8.5		23.3	6.9	
Feel less alone			.000			.000			.000
Yes	33.3	6.1		33.5	6.4		34.9	5.8	
No	27.9	6.1		27	7		30.2	6.5	
Feel more empowered			.000			.000			.001
Yes	33.2	6.2		33.6	6.2		34.8	5.9	
No	28.3	6.1		27.3	7.9		30.9	6.6	
Feel support through rough times			.027			.000			.007
Yes	32.9	6.1		34	5.8		34.8	5.8	
No	30.6	7		29	7.9		32.1	6.6	
Learn new diabetes management strategies			.004			.000			.000
Yes	32.7	6		33.3	6.3		34.62	6	
No	28.2	7.5		26.3	8.1		29.5	5.8	
Learn research and treatment alternatives			.001			.000			.012
Yes	32.8	6.1		33.1	6.3		34.4	5.9	
No	27.5	7.2		26	8.6		30.3	7.3	

Table 6.3
Cont'd.

	DOC Competence			DOC Caring/Goodwill			DOC Trustworthiness		
	Mean	*SD*	*p*-value	Mean	*SD*	*p*-value	Mean	*SD*	*p*-value
Get answers to diabetes questions			.001			.000			.000
Yes	33	6.2		33.7	6		35	5.9	
No	28.6	6.8		26.7	8.1		29.9	5.9	
Learn about potential side effects of drugs/devices			.006			.001			.002
Yes	33	6.3		33.4	6.1		35	5.8	
No	30	6.7		29.7	8.4		31.8	6.6	
Learn things that my healthcare provider didn't know			.029			.026			.028
Yes	32.9	6.1		33	6.7		34.7	5.7	
No	30.5	7		30.4	7.5		32.5	6.9	
Learn strategies to improve insurance coverage for diabetes related medications/supplies/tools			.012			.002			.009
Yes	33.3	6.3		33.7	6.2		35	5.8	
No	30.7	6.5		30.4	7.7		32.5	6.5	
Discussed a topic learned from DOC with my healthcare provider			.279			.008			.389
Yes	32.5	6.2		33.4	6.6		34.3	6.1	
No	31.4	6.8		30.5	7.4		33.4	6.3	

Note. N=178

competence score was 29.8 (*SD*=5.5), the mean diabetes healthcare provider team caring/goodwill score was 32.8 (*SD*=9.1), and the mean diabetes healthcare provider team trustworthiness score was 36.1 (*SD*=7.4) from a range of 0-42. Cronbach's alpha for the diabetes healthcare team were competence (α=.90), caring/goodwill (α=.95), and trustworthiness (α=.93).

Relationships were identified between DOC and diabetes healthcare team source credibility scores (see Table 6.4). DOC competence and trustworthiness positively correlated with diabetes healthcare team trustworthiness. There were no relationships between DOC caring/goodwill and diabetes healthcare team competence or caring/goodwill.

There were differences in how all participants scored source credibility when comparing the DOC and their healthcare provider team. Participants scored their diabetes healthcare team (*M*=33.5, *SD*=8) significantly higher than the DOC (*M*=32, *SD*=6.4) with regard to competence ($p<.05$). Further, participants scored their diabetes healthcare team (M=36.3, SD=7.1) significantly higher than the DOC (*M*=33.6, *SD*=6.2) with regard to trustworthiness ($p<.001$). There was no statistically significant difference in how participants scored DOC and diabetes healthcare team caring/goodwill.

There were similarities and differences in how DOC and diabetes healthcare team source credibility were associated with diabetes self-care, DOC intensity, DOC engagement, bonding and bridging social capital, and health-related quality of life (see Tables 6.2 and 6.5). DOC and diabetes healthcare team source credibility were similar in that all source credibility factors correlated

Table 6.4
Pearson's Product Correlations Between DOC and Diabetes Healthcare Team Source Credibility

	Diabetes Online Community		
	Competence	Caring/Goodwill	Trustworthiness
Diabetes Healthcare Team Competence	.098	.115	.148
Diabetes Healthcare Team Caring/Goodwill	.152*	.119	.140
Diabetes Healthcare Team Trustworthiness	.257**	.137	.270***

Note. *=p<.05, **=p<.01, ***=p<.001. N=178.

with diabetes self-care. Conversely, while DOC source credibility was associated with DOC intensity, DOC engagement, and bonding and bridging social capital, diabetes healthcare team source credibility correlated with health-related quality of life.

Help and Harm

The greater majority of DOC participants (69.8%) reported they or differences in DOC source credibility scores for caring/goodwill and levels of help someone they knew were helped by following advice or health information on the DOC, although, several participants (27.3%) weren't sure. Those with type 1 diabetes (count 88, expected count 84.4) or LADA (count 16, expected count 14) were more likely to report any level of help from the DOC when compared to

Table 6.5
Pearson's Product Correlations for Diabetes Healthcare Team Source Credibility

	Diabetes Healthcare Team		
	Competence	Caring/Goodwill	Trustworthiness
Diabetes Self-Care	.188*	.176*	.195*
DOC Intensity	.038	.008	.054
DOC Engagement	.117	.128	.148
Bonding Social Capital	.000	-.012	.002
Bridging Social Capital	.124	.114	.129
Physical HRQOL	.214**	.234**	.195*
Mental HRQOL	.268***	.340***	.247***

Note. *=p<.05, **=p<.01, ***=p<.001. N=178

those with type 2 diabetes (count 16, expected count 21.6) p<.05. There were differences in DOC source credibility scores for caring/goodwill and levels of help from the DOC $F(2, 166)=5.29$, p<.01. Those who reported the DOC provided any level of help (M=33.1, SD=6.2) had higher DOC caring/goodwill scores than those who reported "don't know" (M=29.3, SD=8.8).

There was a very small percentage (1.8%) of participants who reported they or someone they knew had been harmed by following the advice or health information found on the DOC and the degree of harm was deemed minor. Nearly half (45%) of DOC participants reported that they didn't know if harm had taken place. Participants were more likely to report the were unsure if they had been harmed (count 37, expected count 29) if they had learned something from the DOC their healthcare provider didn't know compared those who had learned

something (count 35, expected count 43), X^2 (2, $\underline{N}$=164)=6.63, p<.05. There was a significant difference in how DOC users reported harm as it relates to DOC competence factors. Participants had higher DOC competence scores if they reported no harm (M=33.1, SD=6.2) than those who reported "don't know" (M=30.7, SD=6.7), F(2, 166)=3.53, p<.05 and had higher DOC caring/goodwill scores if they reported no harm (M=33.3, SD=6) than those who reported "don't know" (M=30.7, SD=8.2), F(2, 165)=3.67, p<.05. Further, participants had higher DOC trustworthiness scores if they reported no harm (M=35, SD=5.8) than those who reported "don't know" (M=32.4, SD=6.6), F(2, 161)=4.3, p<.05. There were no significant differences in the report of being harmed by age, gender, or diabetes type.

Comparison of Baby Boomer Source Credibility, Help, and Harm

Baby boomers were compared to younger adults with regard to demographic factors, DOC and healthcare provider source credibility, help, and harm. Baby boomers were more likely to be living in the United States and more likely to have type 2 diabetes or LADA than younger adults (see Table 6.1). There were no significant differences among groups regarding gender, education level, income, or presence of insurance. There were no significant differences for DOC source credibility factors (competence, caring/goodwill, or trustworthiness), help, or harm. When looking at diabetes healthcare team source credibility, baby boomers (M=34.61, SD=9.0, p<.05) found their diabetes healthcare provider

team to having more caring/goodwill than younger adults (*M*=31.46, *SD*=9.0). There were no significant differences between groups with regard to diabetes healthcare provider competence or trustworthiness factors.

Qualitative Results

Twenty baby boomer DOC users from the United States were interviewed. Participants were 56 years old (range 46-64, *SD*=4.96), female (55%), White (95%) with type 1 diabetes (60%). Through a directive content analysis, the coding schema supported the 6 credibility issue categories and related subcategories as identified in Apomediation Theory (Eysenbach, 2008b). Representative quotes for each category and subcategory are provided in Table 6.6.

Participants described the importance of expertise, as it related to themselves or others in being able to provide credible information as it related to day-to-day diabetes management. Participants reported a potential bias, by bestowing more credibility to opinions rather than facts, although this had the fewest codes to support this category. Source credibility was based on the believability of their DOC peers (apomediaries). Further, source credibility was weighted heavily by the information shared by DOC peers and the believability of these peers for information related to day-to-day diabetes management. Message credibility was based on an understandable language and knowing or having experienced issues personally. Participants described individuals who posted frequently or authors of popular blogs or DOC sites as hubs of credible

Table 6.6

Participant Credibility Values Aligned with Credibility Issues Identified in Apomediation Theory

Credibility issue categories drawn from Apomediation Theory (Eysenbach, 2008b)	Subcategories drawn from definitions of each credibility issue identified in Apomediation Theory (Eysenbach, 2008b)	Examples of how participants described these credibility issues
Expertise	Based on first-hand experience or that of peers	They tend to just give you information based on their experience. I rarely see anyone say, "this is what you need to do". I have seen a lot people post, "this is what I do, you'll have to decide whether this could work for you." For medical advice, go to medical people. For good real world advice, you go to peers with serious experience.
Bias	May bestow more credibility to opinions rather than facts	I find that manufacturer has to only tell you what the FDA allows them to say. They don't always give you the best advice to deal with your situation. I'm a heavy sweater. How do I deal with keeping these infusion devices bound on my body when I have heavy sweating? There's no information out there from the manufacturers. There are good recommendations from a lot of [DOC] users. Seeing what people were doing to be successful with diabetes I've never been exposed to before.
Source credibility	Based on believability of apomediaries	Part of it is I kind of go with my gut and I take things in context with the things that people are saying and how knowledgeable they seem to be, how good of control they seem to have. Are things going well, are they not going well?

Table 6.6
Cont'd.

Credibility issue categories drawn from Apomediation Theory (Eysenbach, 2008b)	Subcategories drawn from definitions of each credibility issue identified in Apomediation Theory (Eysenbach, 2008b)	Examples of how participants described these credibility issues
Source credibility cont'd.	Based on believability of apomediaries cont'd.	If you have 10 people agreeing with each other about a specific issue, I feel pretty comfortable that I'm probably getting pretty good information. On the other hand, if I asked a question and had half a dozen people arguing about it, I would question. I would be very cautious about it.
	Message credibility and credibility of apomediaries are more important than source credibility	I think that's the most frustrating thing and the people who are in Medicine who learned about diabetes 30 years ago and that's all they ever need to know are those two days that they had on diabetes and they know everything. So sometimes, I guess that's one reason it is good to have the online community is to talk to other diabetics who have dealt with stuff and do know. I'm sure my [certified diabetes educator] could probably tell me that same thing, but at the same time my [certified diabetes educator] probably has never been through it. So I'd rather get the information from someone who actually knows what I'm talking about.
Message credibility	Based on understandable language	There are posts and threads and there are even pages for pump users so you can talk about it. You can talk about those with tubing and those without, where you can test things and how they can be linked up to the computer.

Table 6.6
Cont'd.

Credibility issue categories drawn from Apomediation Theory (Eysenbach, 2008b)	Subcategories drawn from definitions of each credibility issue identified in Apomediation Theory (Eysenbach, 2008b)	Credibility issue categories drawn from Apomediation Theory (Eysenbach, 2008b)
Message Credibility cont'd.	Based on understandable language cont'd.	Even if you're not depressed, you're carrying the load all the time. It's a 24/7 juggling act, constantly doing that balancing act to go not too high and not too low and eat right, get your exercise in, and carry on with the rest of your life. And sometimes, you just do need the support, or you have a question, or you need to vent and [the DOC] is an outlet, especially if your family is tired of it.
	Knowing or having experienced issues personally	I guess one of the great things, especially for an older person like me who didn't grow up being on the computer, is being able to hear the stories of people that are, have been, or going to go through the same thing you are.
		I went from 13 point [A1C] now to 5.5 and my endocrinologist gets mad about that. I wanted him to be really thrilled about it and I don't understand why he's really mad about it so this has created a conversation. Then I've read that conversation from start to finish and everybody has an opinion. Some of them make a lot more sense to me than others, but then that's given my own history of lows and my own history of attempting to get in better control.

Table 6.6
Cont'd.

Credibility issue categories drawn from Apomediation Theory (Eysenbach, 2008b)	Subcategories drawn from definitions of each credibility issue identified in Apomediation Theory (Eysenbach, 2008b)	Credibility issue categories drawn from Apomediation Theory (Eysenbach, 2008b)
Credibility hubs	Dynamic (opinion leaders)	I generally look at who posted because there are some posts on there from people who are very, very knowledgeable, and you can tell because they're [name omitted], who's been a diabetic since 1945 and completely complication free. Length of time being a diabetic goes a long way for me as far as whether I believe or I don't believe it. Also, intelligence of the posts. I try to get to know the person, how they go about obtaining their information, if they are actually doing any research or if they are just repeating something that they heard. You gotta use your head. You have to listen to what people are telling you, but don't just take everything for face value. You are talking about your life here.
Credibility evaluations	Spectral	I generally look at information from people I know, but also sometimes I'll look at a forum when I search a topic I'm interested in. I'll look to see how the discussion is going and to see if there is some general consensus. I really don't take anything at face value. I know this disease…I really have to look into things very carefully. I'm really good at going to diabetes-specific websites and seeing what other people are doing, getting information - maybe links to studies or articles. I sort of seek out information online and then see what other people think about it and then digest it all to see how it works for me.

information. Finally, credibility evaluations were spectral, meaning that DOC users were highly interested in the topic of diabetes and had a methodical system in place to evaluate credibility. This system included fact-checking sources.

Discussion

The purpose of this study was to describe how participants perceived source credibility of the information found within the DOC and their diabetes healthcare provider team; examine differences in DOC source credibility, help, and harm among baby boomers and younger adult counterparts; and qualitatively describe if baby boomer DOC users viewed the DOC as an apomediated environment with regard to credibility.

Baby boomer DOC users perceived the credibility of the information found within the DOC, and if the DOC has the potential to help or harm similar to younger adults. Baby boomers have been described as being more trusting of online health information than older adults (Zulman, Kirch, Zheng, & An, 2011). Further, similar to younger adults, trust in health information found in newspapers, magazines, television or government health agencies transfers to trust in online health information (Ye, 2010). While there are obvious differences among generational cohorts, with regard to perception of DOC credibility, help, and harm there appear to be no considerable differences.

Overall, the DOC was seen as helpful. Findings were similar to a national survey of the general population (Fox, 2011). Peer health driven information,

such as shared experiences, support, and understanding, can provide users with a sense of normalcy and social connectedness. Putnam (2001) found that social connectedness is a strong predictor of altruism. DOC users were helped by helping others. Altruism, which has been identified in other chronic disease social networking research (Oh, 2012; Reeves et al., 2014; van Uden-Kraan et al., 2008), may provide an explanation for this finding. Parallel to findings from a national survey of the general population (Fox, 2011), very few participants reported being harmed by the DOC, although the marked difference in participants who weren't sure if they were helped or harmed by the DOC, warrants further study.

DOC source credibility was associated with high diabetes self-care and high social capital. DOC users were able to validate their experiences through homogenous DOC users, while gaining diverse information from heterogeneous DOC users to improve self-care. Interestingly, DOC users who felt supported by their healthcare provider to use the DOC found the information on the DOC to be more credible and helpful.

DOC users found information from their healthcare providers to be more competent and trustworthy than the information found on the DOC. Those with chronic conditions tend to fact check information found online with their healthcare providers (Fox & Duggan, 2013; Hu, Bell, Kravitz, & Orrange, 2012), which was also found in this study. While healthcare provider information is seen as more trustworthy than online information, individuals tend to turn to the Internet first (Hesse et al., 2005). Research suggests that trust in healthcare

provider information is not associated with online health seeking behavior (Hu et al., 2012). Individuals seek online health information to fill a gap in their healthcare needs. The DOC appears to fill a void in the current healthcare system with regard to day-to-day support (see Chapter 5). Healthcare providers need to understand that while they are key sources for health information, they are amongst a large network of potential health information sources (Fox & Duggan, 2013; Sillence, Briggs, Harris, & Fishwick, 2007) which may include family, friends, the Internet, and peers with a similar condition.

Qualitative results indicate the DOC is viewed as credible by its users, although there were instances of misinformation that did require DOC users to carry out additional research. There were certain aspects participants looked for to determine credibility, which aligned with those identified in Apomediation Theory (Eysenbach, 2008a, 2008b) in several ways. First, DOC users were deemed as experts in living with diabetes, traditional credentials did not matter. Second, there were examples of DOC users being biased, imparting more credibility on opinions instead of evidence. Third, credibility was based upon believability of the DOC users and their message, not authority. Fourth, DOC users had a shared language based on having experienced diabetes and were not bothered with precise language. Fifth, credibility hubs were dynamic and related to opinion leaders, such as popular bloggers or individuals highly connected within the DOC, not medical experts. Finally, credibility evaluations were spectral (shades of grey) opposed to binary (black and white) (Eysenbach, 2008b). For example, individuals who sought information about a diabetes

question didn't typically find a single answer. Instead they found array of potential options to sort through based on the experience of others. Spectral credibility evaluations in this study were similar to how they have been described in other research (Fogg & Tseng, 1999); DOC users had high interest in diabetes related discussions; ability to process the diabetes related information cognitively and based on their own clinical situation, high familiarity with diabetes, and considerable opportunity to compare various sources.

This is the first study known by the author to identify source credibility within the DOC. Using a concurrent mixed-method, this study indicates DOC users find the information found on the DOC to be credible. There were differences in how credibility was viewed when comparing DOC credibility to diabetes healthcare team credibility. The DOC was viewed as helpful with very few individuals reporting harm, although there were some still on the fence. When compared to the general population, DOC users found the information on the DOC to be more helpful. The findings have several implications, which are discussed below.

Limitations

This study has limitations. The data used in this study were a secondary analysis of a larger study (see Chapters 4-5). The sample was overwhelmingly White and living in the United States, which may not be representative of the entire DOC. Further, this study looked only at those who could read English. Individuals engaged in non-English DOC sites (i.e., EstaTuDiabetes) may elicit

different results. Only baby boomers were interviewed in this secondary analysis. Thus, qualitative findings cannot be generalized to DOC users of other generations. DOC source credibility measured a collection of information from all individual DOC users when in fact a DOC user may rely on information from select individuals and/or avoid information from others. For those individuals who reported harm, it is unknown if that harm caused physical or mental harm, or another form of harm. Finally, due to self-selection, generalizations should not be made.

Conclusion

This is the first study to identify how a sample of DOC users viewed DOC and diabetes healthcare provider source credibility, and help and harm within the DOC. DOC users found the health information on the DOC to be credible and employ a process to evaluate credibility and described in Apomediation Theory (Eysenbach, 2008a, 2008b). Those using the DOC reported being helped by the DOC with practically no harm reported, suggesting DOC is beneficial with low risk. There were no differences in perception of DOC credibility, help, or harm between baby boomers and younger adults. DOC credibility was associated with high diabetes self-care and high social capital, both indicators of health in individuals with diabetes. DOC users found information from their healthcare providers to be more competent and trustworthy than the information found on the DOC, suggesting that DOC users still find their healthcare provider valuable,

despite their DOC use. Future research as it relates to being helped or harmed by the DOC is warranted.

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CHAPTER 7

CONCLUSION

Summary

The overarching purpose of this research was to better understand peer health within the nonmoderated, nontrained peer context. This research utilized a multiple method approach to examine DOC adult users, health indicators, and credibility through the use of an online survey (Specific Aim 1 and 3); and qualitatively analyze the experiences of DOC use from a select population of users, baby boomers, through telephone interviews (Specific Aims 2 and 3).

Specific Aim 1 was to describe the findings of an online survey, discussing characteristics of DOC users and identify relationships and interactions between those characteristics. The results of this aim are reported in Chapter 4. The major findings of the study were threefold: 1) individuals with high DOC engagement scores were more likely to have better glycemic control; 2) DOC users have high levels of diabetes self-care, HRQOL, and social capital; and 3) healthcare provider knowledge of DOC use was associated with higher DOC intensity, DOC engagement, and social capital.

Specific Aim 2 used a qualitative approach to describe baby boomers' perceptions of their experience with the DOC. The results of this aim are reported

in Chapter 5. Baby boomers were using the DOC to increase their knowledge in order to improve self-care and for mutual understanding and support among DOC users who had shared experiences. The DOC was used in adjunct to, not in place of, regular healthcare visits, filling a gap with regard to tacit knowledge and support. DOC users actively sought out ways to help others and advocated DOC participation. Using a synergistic approach, the DOC provided a mechanism to heal and empower both individual users and the community at large. Through a methodical evaluation process, DOC users analyzed information to determine credibility and relevance. DOC users sought ways to avoid unwanted encounters with regard to cyber-bullying and rude behavior. Participants valued the wisdom of experienced individuals, “diabetes elders” and aspired to become a diabetes elder aging forward. Further, understanding age-related experiences of peers allowed participants to anticipate diabetes management and other health-related changes as they became older.

Finally, Specific Aim 3 examined how baby boomer DOC users describe credibility, help, and harm within the DOC. Results of this aim are reported in Chapter 6. A mixed method approach was utilized in order to triangulate data as it related to credibility. Apomediation Theory (Eysenbach, 2008a, 2008b), a theory that has yet to be analyzed within a research platform, was examined using framework analysis as it relates to credibility issues within the DOC. Results indicated that participants employed a process, similar to what has been described in Apomediation Theory, to find credible health information through the guidance of apomediaries or peers. Overall DOC users found the DOC to be

helpful with very little harm reported, suggesting its use is beneficial with low risk. There were positive associations between both credibility and both diabetes self-care and social capital. Finally, DOC users found information from their healthcare provider team to be more competent and trustworthy than the information found on the DOC, suggesting that DOC users still find their healthcare providers valuable.

Limitations

There were several limitations to this research. First, survey participants were recruited from the two diabetes-specific and two general social media sites that are a part of the DOC. Therefore, due to sample self-selection, caution should be taken with regard to generalization of findings. For example, participants who were more engaged in the DOC may have been more likely to participate in this study. Additionally, this study did not specifically identify "lurkers" and how their results might be similar or different.

Second, it is difficult to determine a response rate for online surveys. One way a response rate can be calculated is by taking the ratio of actual survey responses to unique site visitors. This calculation was done and resulted in a response rate of 12.2%. While this may appear low, a response rate of <.01% is not unusual (Eysenbach, 2004). The original sample size sought for this study was 948, due to unforeseen issues with recruitment, additional recruitment sites were added. Despite an expansion of the study, 183 was the largest sample that could be attained. This sample size was adequate to statistically determine

significant differences, indicating that future studies should question very critically whether large samples can be recruited easily among online health communities.

Respondents were overwhelmingly White with most online survey and all interviewed participants living in the United States, which may not be an accurate reflection of the entire DOC population. The results of this study cannot be generalized to non-English speaking DOC sites (i.e., EstaTuDiabetes). This study only sampled adult DOC users and findings should not be generalized to minors or caregivers participating in the DOC.

Overall DOC participants had good glycemic control and diabetes self-care behaviors. As noted above, bias regarding self-selection must be considered. Further, self-reporting of A1C may affect reliability of data; however, research has shown that reported a >92% reliability of self-reported diabetes data over time (Schneider, Pankow, Heiss, & Selvin, 2012). Similar A1C results have been found among international DOC users, in which the average A1C was 6.9% (Weitzman, Adida, Kelemen, & Mandl, 2011). Further, some DOC participants have been found to share their A1C levels with others online (Weitzman et al., 2011), and have gone as far as including a photograph of their lab record. This transparency in sharing health information among some DOC users may improve reliability in reporting, although A1C documentation was not requested for this study.

Interviewed participants included baby boomer DOC users only. Qualitative findings should not be generalized to younger or older cohorts of DOC users. Again, due to self-selection, those baby boomer DOC users who

agreed to participate in the interview may have different use patterns, credibility evaluations, and views of the DOC than DOC users of different ages. While it is clear that older adults have lower rates of Internet use, baby boomers have widespread uptake of Internet use with rapid growth of Web 2.0 technologies (Fox, 2011; Zickuhr, 2010), thus substantiating the need to study baby boomers as it relates to e-health.

In directive content analysis, an existing theory can be supported and extended (Hsieh & Shannon, 2005). However, when utilizing a preexisting theory, researchers may be predisposed to bias based on previous knowledge. This bias could increase the likelihood that data would be found to be more supportive, rather than nonsupportive, of the theory. Reflexivity, the process of systematically documenting the context of knowledge construction and how this knowledge is affecting the researcher (Cohen & Crabtree, 2006) took place and included the use of a reflexive journal.

The nature of this research cannot determine causality. It is unknown if the high DOC engagement results in high self-care and optimal glycemic levels, vice versa, or if common unknown causal factors induce the association. It is also unknown how time will affect both DOC engagement and other health indicators. The findings do support the need for additional research in this area. Prospective studies, specifically longitudinal randomized control trials, are warranted to better understand the DOC and its impact on health outcomes.

Contributions and Implications

This research is the first of its kind to identify relationships and interactions between engagement in the DOC and health indicators, synergy within an online health community to allow for empowerment and healing among individual users and the group, and credibility of online health information as it relates to Apomediation Theory. Dissemination of this research will contribute to the fields of diabetes, chronic disease, aging, and e-health with many stakeholders who will benefit. Once disseminated, study results will inform patients with diabetes, the DOC, theorists, diabetes treatment providers (physicians, nurse practitioners, physician assistants, certified diabetes educators, registered nurses, registered dietitians, mental health professionals, etc.), hospitals and clinics, state health departments, professional organizations, and policy makers about nonmoderated, nontrained peer health within the DOC.

This study indicated a relationship between DOC engagement and better glycemic control. The DOC is a cost-effective supplement to usual diabetes care that can fill a gap in the current healthcare system with regard to increasing knowledge and support for day-to-day diabetes management, although only available to those with Internet access. DOC use did not decrease healthcare provider visits and was found to be helpful with regard to increasing tacit knowledge and support. Further, DOC users found the DOC to be credible, through a credibility evaluation process, and helpful. With diminutive harm reported, and significant benefits identified from the collective wisdom of DOC users, healthcare providers and policy makers should consider recommendation

of DOC use for individuals with diabetes as an adjunct to existing care. In fact, there are some healthcare systems and providers who are already recommending the DOC. For example, Sutter Health, a network of physicians, hospitals, and home health agencies has collaborated with the president of the American Academy of Diabetes Educators to create a handout of diabetes information resources, including DOC sites (D. Greenwood, personal communication, November 17, 2014). Further, the president elect of the American Academy of Diabetes Association has a direct link to DOC resources on her professional website (Warshaw, 2012). In addition, several professional educational conferences have included keynote speakers from DOC leaders to promote awareness of the DOC among healthcare providers, including the Joslin Diabetes Center, Juvenile Diabetes Research Foundation, American Academy of Diabetes Educators, Endocrine Society, Med X, Health 2.0, Medicine 2.0, and World Diabetes Congress.

Findings from this study also indicate that baby boomers who use the DOC will find value in continued use of DOC as they age forward. DOC users anticipated they would use the DOC to identify age related changes with regard to their own health and diabetes management, and to help younger DOC users as they age as well. Altruism, identified among baby boomers in this research, provided a foundation of diabetes knowledge and support for the next generation of DOC users, suggesting the presence of generativity. Generativity, the seventh stage of identity in the life cycle (Erikson, 1980), can promote successful aging (Schoklitsch & Baumann, 2012), such as enhancing physical functioning and

longevity (Gruenewald, Liao, & Seeman, 2012), which could be an added benefit to DOC use. The majority of baby boomers are currently using the Internet (Fox, 2011) and may continue to do so as they age. An increased number of older adults using the Internet will drive the need for aging-specific access to health information and peer health, though it may increase the digital divide for those with low health literacy (Levy, Janke, & Langa, 2014) and/or no Internet access. With the increased need of healthcare providers to support the aging population (Olshansky, Goldman, Zheng, & Rowe, 2009; Ricketts, 2011) and their chronic conditions, such as diabetes, the DOC may provide benefit to the tsunami of aging baby boomers and the healthcare system.

The identification of the role of diabetes elders within the DOC was an unexpected yet important finding in this research. While diabetes experiential years and chronological years were both noted as being important, more weight was placed on living successfully with diabetes over a number of years, regardless of chronological age. There are several implications. Older adults may be seeking advice about “growing old” with diabetes from individuals who are chronologically younger than them, which may appear counterintuitive. Younger peers are also looking to diabetes elders to learn about successes, struggles, and the overcoming of struggles. Diabetes elders are a critical component of the DOC, informing and motiving both younger and older peers. Healthcare providers and health systems should understand the role diabetes elders could play in their practice with regard to peer support. Finally, given that the incidence of type 1 and type 2 diabetes in childhood is rising (Dabelea et al., 2014; Vehik & Debelea,

2011) and that life expectancy in diabetes is increasing (Miller et al., 2012), over time there will be a surge in the number of individuals who reach old age with decades of diabetes experience. The changing landscape of not only older adults with chronic disease, but older adults with long-standing chronic disease, will inform healthcare providers, newly diagnosed individuals with diabetes and their families, that longevity in diabetes can be achieved with proper care.

Apomediation theory posits that e-patients are guided to credible information. Findings of this study suggest that apomediaries, or DOC users, could also anticipate and guide individuals to aging related information in a process similar to anticipatory guidance, a proactive counseling technique routinely used by healthcare providers in the pediatric setting in which guidance is provided to parents based on the developmental stages of their children (Christophersen, 1986). Guidelines for anticipatory guidance are lacking among aging cohorts due to variations in health. While healthcare providers cannot provide clear cut guidelines regarding what may or may not occur as individuals age, DOC users can engage in the DOC and identify peers with age-related experience who can provide some anticipation of age related changes. Understanding age-related changes among those with diabetes is particularly important given the increased incidence of geriatric conditions among adults over the age of 50 with diabetes (Cigolle et al., 2011). This type of aging-related anticipatory guidance not only provides DOC users with more information to aid current healthcare decisions, but also informs them about future diabetes management and caregiver needs as well as healthcare costs related to

Medicare (for those living in the United States). While not studied in this research, this aging-related anticipatory guidance may also inform caregivers of individuals with diabetes.

Individuals are turning to the Internet for health-related purposes whether their healthcare providers are aware of it or not. Instead of being afraid of the unknowns of what can be found on the Internet, this research supports healthcare providers being proactive in seeking out online resources they trust and recommending them to patients. These online resources should include DOC sites, such as specific blogs or individuals to follow within the DOC, who are notable for sharing credible information. In addition, healthcare providers can utilize the DOC to better understand what it is like to really live with diabetes, as seen in the Fakebetes Challenge (Litchman, 2012; Vlasnik, 2014). Doing so may provide greater understanding on the importance of peer health. Finally, healthcare providers need to introspectively identify how they feel about patients gaining information and support from sources other than themselves. Healthcare providers may feel insecure about how patients using the DOC value medical opinions compared to peer information. This research indicates that the DOC is being used as a supplement to traditional health care replacement to traditional, not a replacement.

Future Research

The findings from this research are promising and provide a foundation for future research. There are five areas in which research in this field should be expanded and recommended research is further detailed below.

Research trials should be conducted to examine the psychometric properties of the DOC intensity and DOC engagement scales from this study. Intensity and engagement measures in online health communities have been inconsistent among various disease states (Batenburg & Das, 2014; Cobb, Graham, Bock, Papandonatos, & Abrams, 2005; Petrovčič & Petrič, 2014; Poirier & Cobb, 2012; Strecher et al., 2008; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009). In this study, the DOC intensity scale measured emotional connectedness to the DOC and integration of the DOC into daily use while the DOC engagement scale measured the level to which participants provided or received commentaries or posts as it related to clinical information, guidance, and support. Both scales had adequate Cronbach's alpha levels. Principle component and factor analysis should be examined amongst a large, global sample of adult DOC users to determine concurrent and convergent validity of the constructs being measured. Once validated in a sample of adult DOC users, further research should be conducted to determine if the DOC intensity and DOC engagement scales are able to accurately capture intensity and engagement in minor or caregiver DOC users, and other chronic condition based online communities.

While patient-provider relationship and communication play a role, the association between DOC engagement and better glycemic control warrants an evaluation of current healthcare provider knowledge of the DOC and how its use might affect patients. Pre-post testing using focus groups should be conducted amongst endocrinologists, diabetologists, certified diabetes educators, and family practice providers who provide diabetes care to determine level of knowledge and comfort levels recommending DOC use. Research participants should then be given a sampling of DOC sites to examine or participate in, including forums, blogs, vlogs, and/or tweetchats. After these DOC sites had been accessed, healthcare providers would undergo posttesting evaluation to determine if their views had or had not changed and why.

Diabetes burnout has been well described (Fritschi & Quinn, 2010; William H Polonsky, 1999; W. H. Polonsky, 2002) and the DOC is seen as a resource to mitigate diabetes burnout. However, little information is known about social media burnout within the context of online health communities. While the DOC may help individuals manage the emotional side of diabetes management, anecdotal information (Kelly, 2014; Nimlos, 2014; S., 2014; Weaver, 2014) indicates social media burnout, or “DOC burnout” can also occur. Coulson and Shaw (2013) found that patient moderators have personal emotional challenges related to nurturing an online community. Leadership by select users, including patient moderators, is required to maintain any online community (Butler, Sproull, Kiesler, & Kraut, 2002). If DOC burnout is experienced by those in positions of leadership or influence within the DOC, it may have an effect on the community

structure. It is unknown if DOC burnout exists and to what degree. However, DOC burnout may affect diabetes self-care and other psychological factors and should be further explored.

Findings from this research indicate an association between DOC engagement and A1C, with evidence to suggest high engagement in the DOC results in better glycemic control, although causality cannot be determined. A longitudinal randomized control trial is necessary to determine if DOC use in addition to standard clinical care, as opposed to standard clinical care alone, has any bearing on glycemic control, treatments, and other health indicators. While peer health may not be helpful for all individuals with diabetes (Smith et al., 2011), secondary factors that unite peers, such as gender, culture, age, or shared experience (Heisler, Vijan, Makki, & Piette, 2010) may be necessary for optimal outcomes. In this proposed randomized control trial two separate intervention arms along with a control arm would be employed. In the first intervention arm, participants would be provided with a list of popular DOC sites they would be encouraged to visit. In the second intervention arm, participants would be paired with a DOC user who had previously agreed to assist with this research, based on shared characteristics (i.e., type of diabetes, age, gender, medications or devices), who will help the participant navigate the DOC. For those in the intervention arms, a web analytics toolbar would be installed on the participant's computer to allow for a more precise examination of DOC intensity and DOC engagement as well as information about specific DOC sites visited and connections with other DOC users. Network analysis would determine DOC

users and/or sites that were influencing each participant. Measures to identify how DOC use affects coping, social support, and more precise measures to evaluate empowerment, help and harm would be included. Results from this study would inform causal relationships between DOC use and health indicators, such as A1C, and determine types of DOC sites or DOC users that participants were more engaged in based on demographic or health history variables. Understanding DOC engagement on a demographic and health history level, as well as influential DOC sites and users, will provide healthcare providers with targeted translational data (i.e., which DOC site to recommend for a specific type of patient) when considering the DOC for their patients. This research would require: 1) collaboration with an informaticist with training in web analytics and network analysis, 2) meaningful inclusion of DOC users and other stakeholders in the research design, as identified in Patient-Centered Outcomes Research Institute; and 3) multiple clinical sites across the United States.

This body of research indicates DOC users personally gain from DOC use through increased knowledge and support. Further, DOC users have high levels of HRQOL and diabetes-self-care. However, the relationship regarding the spread of knowledge, support, and health indicators is unknown. In the Framingham cohort, research has indicated that both positive (happiness) and negative (obesity, alcohol consumption) areas of health can be contagious within social networks (Christakis & Fowler, 2007; Fowler & Christakis, 2008; Rosenquist, Murabito, Fowler, & Christakis, 2010). Using the data from the randomized control trial proposed above, longitudinal analyses could determine if

and how improvements in knowledge, support, and health indicators, such as A1C, HQOL, and diabetes self-care behaviors, can spread, and to what degree, within the DOC. Findings from this future study would have significant public and policy implications.

Conclusion

This research is the first of its kind to explore DOC users of this nonmoderated, nontrained online community. While interventional approaches are necessary, it is important to understand users of naturally occurring peer-led online communities, such as the DOC. In this study, DOC use was found to be positively associated with regard to several health indicators, knowledge attainment, and support. Further, DOC users perceived the DOC to be helpful and provide credible information. As the intersection between health and the Internet increases, more research dedicated to determining how online health communities affect health indicators among its users is warranted. Finally, this research provides a deeper understanding of the DOC, and how DOC use can complement the existing healthcare system to provide patient-centered care.

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APPENDIX A

SURVEY QUESTIONS TO ADDRESS

SPECIFIC AIM 1

Survey Questions to Address Specific Aim 1

Demographics

1) What is your gender?
    a. Male
    b. Female
2) What is your marital status?
    a. Single
    b. Married
    c. Divorced
    d. Widowed
3) What is your education level?
    a. Some high school
    b. High school graduate
    c. Some college
    d. Associates degree
    e. Bachelor's degree
    f. Graduate or professional degree
4) What is your employment status?
    a. Student
    b. Unemployed
    c. Working part-time
    d. Working full-time
    e. Retired
    f. Disabled
5) What is your annual household income?
    a. <$30,000
    b. $30,000 - $49,999
    c. $50,000 - $74,999
    d. >$75,000
6) What is your age?
7) What is your ethnicity?
    a. Hispanic or Latino
    b. Not Hispanic or Latino
8) What is your race? (check all that apply)
    a. American Indian or Alaska Native
    b. Asian
    c. Black or African American
    d. Native Hawaiian or Other Pacific Islander
    e. White
9) What Country/State do you live in now?
10) What is your current living setting
    a. Rural
    b. Suburban

c. Urban

11) What best describes your health insurance? (check all that apply)
    a. Uninsured, private pay
    b. Private insurance
    c. Military coverage
    d. Medicaid
    e. Medicare
    f. Medicare Disability

Health History

12) What type of diabetes do you have?
    a. Type 1
    b. Type 2
    c. LADA (latent autoimmune diabetes of adulthood)
    d. GDM (gestational diabetes)
13) How old were you when you were diagnosed with diabetes?
14) What treatments are you currently using to treat diabetes? (check all that apply)
    a. Diet
    b. Exercise
    c. Pills
        i. Metformin (Glucophage, Glucophage XR, Glumetza, Fortamet, Riomet)
        ii. Acarbose (Precose)
        iii. Miglitol (Glyset)
        iv. Nateglinide (Starlix)
        v. Repaglinide (Prandin)
        vi. Chlorpropamide (Diabinese)
        vii. Glimepiride (Amaryl)
        viii. Glyburide (Diabeta, Micronase)
        ix. Glipizide (Glucotrol)
        x. Rioglitazone (Avandia)
        xi. Pioglitazone (Actos)
        xii. Sitaglipitin (Januvia)
        xiii. Saxagliptin (Onglyza)
        xiv. Linaglipitin (Tradjenta)
        xv. Bromocriptine (Cycloset)
    d. Non-insulin injectables
        i. Exenatide Extended Release (Bydureon)
        ii. Exenatide (Byetta)
        iii. Liraglutide (Victoza)
        iv. Pramlintide (Symlin)
    e. Insulin
        i. Humulin N, Novolin N (NPH)
        ii. Humulin R, Novolin R (Regular)

iii. Humulin R U500
iv. Insulin NPH/Regular (Humulin 50/50)
v. Insulin NPH/Regular (Novolin 70/30)
vi. Insulin Detemir (Levemir)
vii. Insulin Glargine (Lantus)
viii. Insulin Aspart (NovoLog)
ix. Insulin Aspart Protamine/Insulin Aspart (NovoLog Mix 70/30)
x. Insulin Glulisine (Apidra)
xi. Insulin Lispro (Humalog)
xii. Insulin Lispro Protamine/Insulin Lispro (Humalog Mix 50/50)
xiii. Insulin Lispro Protamine/Insulin Lispro (Humalog Mix 75/25)

f. Insulin pump
g. Continuous glucose monitoring system

15) My most recent A1C was _____.
16) What type of medical practice do you go to for diabetes care?
a. Endocrinology
b. Internal Medicine
c. Family Practice
d. Community Clinic
e. Other _____
17) Who do you see for your diabetes care? (check all that apply)
a. Physician
b. Nurse Practitioner
c. Physician Assistant
d. Certified Diabetes Educator
e. Dietitian
18) How often do you go see a provider for diabetes care?
a. At least monthly
b. Every 3 months
c. Every 6 months
d. Once a year
e. More than once a year
19) Have you been diagnosed with: (check all that apply)
a. Eye disease (retinopathy)
b. Heart disease (high blood pressure, high cholesterol, stroke, heart attack)
c. Kidney disease (microalbuminuria, renal insufficiency, chronic kidney disease, dialysis)
d. Neuropathy
e. Gastroparesis
f. Erectile Dysfunction (men only)
g. Skin ulcers
h. Depression

i. None of the above

Health-Related Quality of Life

SF12-V2

20) In general, would you say your health is: 1= Excellent, 2=Very Good, 3=Good, 4=Fair, 5=Poor

The following two questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

21) Moderate Activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf:
1= Yes, Limited a Lot, 2= Yes, Limited a Little, 3= No, Not Limited at All

22) Climbing several flights of stairs?
1= Yes, Limited a Lot, 2= Yes, Limited a Little, 3= No, Not Limited at All

During the past 4 weeks have you had any of the following problems with your work or other regular activities as a result of your physical health?

23) Accomplished less than you would like: Yes = 1, No = 2

24) Were limited in the kind of work or other activities: Yes = 1, No = 2

During the past 4 weeks, were you limited in the kind of work you do or regular activities as a result of any emotional problems (such as feeling depressed or anxious)?
25) Accomplished less than you would like: Yes = 1, No = 2

26) Didn't do work or other activities as carefully as usual: Yes = 1, No = 2

27) During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? 1= Not at all, 2= A little bit, 3=Moderately, 4=Quite a bit, 5=Extremely

The next 3 questions are about how you feel and how things have been during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks -
28) Have you felt calm and peaceful? 1= All of the time, 2=Most of the time, 3=A good bit of time, 4=Some bit of time, 5=A little of the time, 6= None of the time

29) Did you have a lot of energy? 1= All of the time, 2=Most of the time, 3=A good bit of time, 4=Some bit of time, 5=A little of the time, 6= None of the time

30) Have you felt downhearted and blue? 1= All of the time, 2=Most of the time, 3=A good bit of time, 4=Some bit of time, 5=A little of the time, 6= None of the time

31) During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? 1= All of the time, 2=Most of the time, 3=A good bit of time, 4=Some bit of time, 5=A little of the time, 6= None of the time

Web 2.0 Application Use

32) When accessing the Internet, I use (check all that apply)
- Personal laptop
- Personal Netbook
- Tablet (iPad, Samsung Galaxy Tab, etc.)
- E-Reader (Nook, Kindle, etc.)
- Mobile phone
- Computer at home
- Computer belonging to a friend or family member
- Computer at school
- Computer at work
- Computer at the library

33) How long have you been a member of TuDiabetes or another DOC site?
a. <3 months
b. 3-12 months
c. 1-2 years
d. 2-3 years
e. 3-4 years
f. 4-5 years

DOC Intensity Score

1-6 Response categories range from 1 = strongly disagree to 5 = strongly agree

34) TuDiabetes or another DOC site is part of my everyday life
35) I am proud to tell people I am on TuDiabetes or another DOC site
36) TuDiabetes or another DOC site has become part of my daily routine
37) I feel out of touch when I haven't logged onto TuDiabetes or another DOC site for awhile
38) I feel I am part of the TuDiabetes or another DOC site community
39) I would be sorry if TuDiabetes or another DOC site shut down

40) Approximately how many TOTAL TuDiabetes or another DOC site friends do you have?
41) In the past week, on average, approximately how much time PER DAY have you spent actively using TuDiabetes or another DOC site?

Internet Social Capital Scale

Bonding Subscale

42) There are several people on TuDiabetes or another DOC site I trust to help solve my problems
43) There is someone on TuDiabetes or another DOC site I can turn to for advice about making very important decisions.
44) There is no one on TuDiabetes or another DOC site that I feel comfortable talking to about intimate personal problems.
45) When I feel lonely, there are several people on TuDiabetes or another DOC site I can talk to.
46) If I needed an emergency loan of diabetes supplies, I know someone on TuDiabetes or another DOC site I can turn to.
47) I do not know people on TuDiabetes or another DOC site well enough to get them to do anything important.
48) The people I interact with on TuDiabetes or another DOC site would help me fight an injustice.

Bridging Subscale

49) Interacting with people on TuDiabetes or another DOC site makes me interested in things that happen outside of my town.
50) Interacting with people on TuDiabetes or another DOC site makes me want to try new things.
51) Interacting with people on TuDiabetes or another DOC site makes me interested in what people unlike me are thinking.
52) Talking with people on TuDiabetes or another DOC site makes me curious about other places in the world.
53) Interacting with people on TuDiabetes or another DOC site makes me feel like part of a larger community.
54) Interacting with people on TuDiabetes or another DOC site makes me feel connected to the bigger picture.
55) Interacting with people on TuDiabetes or another DOC site reminds me that everyone in the world is connected
56) I am willing to spend time to support general TuDiabetes or another DOC site community activities.

57) Interacting with people on TuDiabetes or another DOC site gives me new people to talk to.
58) On TuDiabetes or another DOC site, I come in contact with new people all the time.

59) Where do you go for diabetes related information (check all that apply)
    a. Family
    b. Friends
    c. Internet
        - Professional websites
        - Social networking
        - Pharmaceutical websites
        - Durable medical equipment (glucometer, insulin pump, sensor) websites
    d. Medical provider
    e. Magazines (Diabetes Forecast, etc.)
    f. Professional medical journals (Diabetes care, etc.)
60) In comparison to the time you spend on TuDiabetes or another DOC site, how frequently do you visit other social networks for diabetes-related information?
    a. Never
    b. Some of the time
    c. Most of the time
    d. All of the time
61) What percentage of your time on TuDiabetes or another DOC site do you spend (must add up to 100%)
    - Creating original posts
    - Responding to other posts
    - Reading other posts
62) When you access TuDiabetes or another DOC site do you (check all that apply, then prioritize)
    a. Share personal clinical information
    b. Request clinical guidance/feedback
    c. Provide clinical guidance/feedback
    d. Receive emotional support
    e. Provide emotional support
63) Have you or has anyone you know been helped by following advice or health information found on TuDiabetes or another DOC site?
    a. Major help
    b. Moderate help
    c. Minor help
    d. No help
    e. Don’t know
64) Have you or has anyone you know been harmed by following advice or health information found on TuDiabetes or another DOC site?
    a. Major harm

b. Moderate harm
c. Minor harm
d. No harm
e. Don't know

65) Does your healthcare provider support the use of your using TuDiabetes or another DOC site?
a. Yes, I have told my healthcare provider I use TuDiabetes or another DOC site
b. No, I have told my healthcare provider I use TuDiabetes or another DOC site
c. I don't know, I HAVE told my healthcare provider I use TuDiabetes or another DOC site
d. I don't know, I HAVE NOT told my healthcare provider I use TuDiabetes or another DOC site

Reasons to join a DOC

66) Being a member of TuDiabetes or another DOC site helps me to feel more understood
a. Yes
b. No
c. Maybe

67) Since becoming a member of TuDiabetes or another DOC site, I feel less alone
a. Yes
b. No
c. Maybe

68) TuDiabetes or another DOC site has helped me learn about new diabetes management strategies
a. Yes
b. No

69) TuDiabetes or another DOC site has helped me learn about new diabetes related research and treatment alternatives.
a. Yes
b. No

70) TuDiabetes or another DOC site has helped me learn about strategies to improve insurance coverage for medications, insulin pumps, sensors, etc.
a. Yes
b. No

71) TuDiabetes or another DOC site has helped me get answers to many of my diabetes questions.
a. Yes
b. No

72) Since becoming a member of TuDiabetes or another DOC site, I feel more empowered
a. Yes

b. No

73) TuDiabetes or another DOC site has helped me learn about potential side effects of drugs or devices
   a. Yes
   b. No
74) I have learned things about diabetes on TuDiabetes or another DOC site my healthcare provider didn't know
   a. Yes
   b. No
75) I have discussed a topic I learned about on TuDiabetes or another DOC site with my healthcare provider
   a. Yes
   b. No
76) TuDiabetes or another DOC site has provided me with support through rough times.
   a. Yes
   b. No
77) TuDiabetes or another DOC site allows me to help others.
   a. Yes
   b. No
78) TuDiabetes or another DOC site has provided a way for me to make new friends.
   a. Yes
   b. No

Source Credibility

Please indicate your impression of your diabetes healthcare team by circling the appropriate number between the pairs of adjectives blow. The closer the number is to the adjective, the more certain you are of your evaluation.

79)– 96)

Competence

Intelligent	1 2 3 4 5 6 7	Unintelligent
Untrained	1 2 3 4 5 6 7	Trained
Inexpert	1 2 3 4 5 6 7	Expert
Informed	1 2 3 4 5 6 7	Uninformed
Incompetent	1 2 3 4 5 6 7	Competent
Bright	1 2 3 4 5 6 7	Stupid

Goodwill

Cares about me	1 2 3 4 5 6 7	Doesn't care about me
Has my interest at heart	1 2 3 4 5 6 7	Doesn't have my interest at heart
Self-centered	1 2 3 4 5 6 7	Not self-centered

Concerned with me	1 2 3 4 5 6 7	Unconcerned with me
Insensitive	1 2 3 4 5 6 7	Sensitive
Not understanding	1 2 3 4 5 6 7	Understanding

Trustworthiness

Honest	1 2 3 4 5 6 7	Dishonest
Untrustworthy	1 2 3 4 5 6 7	Trustworthy
Honorable	1 2 3 4 5 6 7	Dishonorable
Moral	1 2 3 4 5 6 7	Immoral
Unethical	1 2 3 4 5 6 7	Ethical
Phoney	1 2 3 4 5 6 7	Genuine

Please indicate your impression of the DOC by circling the appropriate number between the pairs of adjectives blow. The closer the number is to the adjective, the more certain you are of your evaluation.

97) – 114)

Competence

Intelligent	1 2 3 4 5 6 7	Unintelligent
Untrained	1 2 3 4 5 6 7	Trained
Inexpert	1 2 3 4 5 6 7	Expert
Informed	1 2 3 4 5 6 7	Uninformed
Incompetent	1 2 3 4 5 6 7	Competent
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Goodwill

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Phoney	1 2 3 4 5 6 7	Genuine

Diabetes Self-Care Behaviors

SCI-R Scale

This survey measures what you *actually do*, not what you are advised to do. How have you followed your diabetes treatment plan in the past 1-2 months?

		Never	Rarely	Some-times	Usually	Always	
115)	Check blood glucose with monitor	1	2	3	4	5	
116)	Record blood glucose results	1	2	3	4	5	
117)	If type 1: Check ketones when glucose level is high	1	2	3	4	5	Have type 2 diabetes
118)	Take the correct dose of diabetes pills or insulin	1	2	3	4	5	Not taking diabetes pills or insulin
119)	Take diabetes pills or insulin at the right time	1	2	3	4	5	Not taking diabetes pills or insulin
120)	Eat the correct food portions	1	2	3	4	5	
121)	Eat meals/snacks on time	1	2	3	4	5	
122)	Keep food records	1	2	3	4	5	
123)	Read food labels	1	2	3	4	5	
124)	Treat low blood glucose with the recommended amount of carbohydrate	1	2	3	4	5	Never had low blood glucose

125)	Carry quick acting sugar to treat low blood glucose	1	2	3	4	5	
126)	Come in for clinic appointments	1	2	3	4	5	
127)	Wear a Medic Alert ID	1	2	3	4	5	
128)	Exercise	1	2	3	4	5	
129)	If on insulin: Adjust insulin dosage based on glucose values, food, and exercise	1	2	3	4	5	Not on insulin

APPENDIX B

INTERVIEW GUIDE TO ADDRESS

SPECIFIC AIM 2

Interview Guide to Address Specific Aim 2

Time for informed consent and introduction to the purpose of the study
Participants will be given time to read the consent document, if they have not already, and ask questions. The study investigator will give a brief (less than 5 minute introduction to the study and its purpose, and that the interview will be recorded. Participants will be asked to provide verbal consent to record the interviews. Participants will be reminded that their participation is voluntary and that they do not have to answer any questions they do not want to answer.

A. Demographics: Tell me a little bit about yourself
B. How did you first come to find out about the DOC?
C. How often do you use the Internet?
    1. For health
    2. For social
D. Where do you primarily access the Internet?
E. Age
F. Education
G. Type of diabetes
H. Type of treatment

Topics will be derived from the themes defined by Apomediation Theory.

A. How has diabetes affected your life?
    a. What kind of emotional challenges have you experienced? (Mental)
        i. Fear
        ii. Anger
        iii. Depression
    b. How has diabetes affected your social life?
        i. Interactions with family/friends
        ii. Interactions with co-workers
        iii. Mealtime
    c. What type of physical challenges do you experience day to day?
        i. Fluctuations in blood sugar
    d. What type of physical challenges have you experienced since your initial diabetes diagnosis?
        i. Complications
    e. What type of personal discipline has developed?
    f. What type of financial implications have you noticed from diabetes?
    g. Where do you typically engage most of your social interactions with others?
B. How do you typically seek help to manage your diabetes?
C. Please tell me about any previous experiences with good healthcare recommendations to manage your diabetes.
D. Please tell me about any previous experiences with poor healthcare recommendations to manage your diabetes.

E. What have been your most positive experiences with managing your diabetes?
F. Where do you look most often for help about diabetes information?
G. How do you typically seek care about any other healthcare issues?
H. Use of intermediaries
    a. Tell me about your experiences with your diabetes healthcare providers.
    b. What types of symptoms or issues do you most likely use your healthcare provider for?
        i. What about acute problems?
        ii. What about standard medical care with your diabetes?
        iii. How often do you engage with your healthcare provider about your diabetes?
    c. What type of symptoms or issues do you mostly likely use the DOC?
        i. What about acute problems?
        ii. What bout standard medical issues with your diabetes?
        iii. How often do you engage with the DOC about your diabetes?
I. Use of disintermediaries
    a. Tell me about your experiences using health oriented websites that aren't social networking sites, blogs, or discussion boards.
    b. Tell me about the type of information you receive.
    c. Tell me about the times in which you have sought help from these types of websites.
J. Use of apomediaries
    a. Tel me about your experiences using the DOC.
    b. Tell me about the type of information you receive.
    c. Tell me about the times in which you have sought help from the DOC.
K. Credibility: Tell me about how you decide if you believe or trust the health information you receive as it relates to
    a. Your diabetes healthcare provider
    b. Health oriented websites
    c. The DOC
L. How do you know if this is good or bad information/recommendations?
M. Do you notice a difference between the sites you visit for diabetes management between nonprofit and for profit sites?
N. Tell me about any experiences you have had clicking on any advertisements with these sites.
O. Relevance: Tell me about how you use the health information you receive from
    a. Your diabetes healthcare provider
    b. Health oriented websites
    c. The DOC
P. What type of self-policing or policing in general do you engage online?

Q. How does your spouse use the Internet?
    a. Compared to you, how does his/her activity and purpose differ?
    b. How does s/he use it for their healthcare needs?
R. Aging
    a. 20 years ago how did you find information about your diabetes or other healthcare issues?
    b. How is that different from today?
    c. How do you see the Internet playing a role in your healthcare over the next 20 years?
    d. Tell me how the DOC will impact you as you age.
    e. How is that different from people who have never accessed the DOC?
S. Closing Questions/Comments
    a. Is there anything else you would like to tell me?
    b. Do you have any questions you would like to ask me?
    c. Do you have any comments or suggestions about the study?
    d. Would you like to hear about the results of the study?

The study investigator will thank the participant for the interview. The study investigator will notify the participant that a $20 donation will be given to the Diabetes Hands Foundation prior to saying goodbye.

APPENDIX C

PILOT STUDY

Pilot Study

A pilot study was conducted using a 91-question survey to determine the following: 1) how long it took participants to complete the survey, 2) if any of the questions were ambiguous or irrelevant, 3) if there were any questions that were unclear, 4) if question choices were inappropriate, 5) if any questions were offensive, and 6) if there were questions that were missed. It is important to note that the pilot included questions from the SF-12, not the SF-12v2 as the questions were not available at the time of the pilot. Seven individuals were invited to review the survey and provide feedback, five have diabetes, and two were diabetes medical providers. Three of those with diabetes are members of TuDiabetes while the other two have been on TuDiabetes but are not members. Two of those with diabetes are members of the Diabetes Advocates. Diabetes Advocates launched in 2010, as a nonprofit organization (NPO) that connects diabetes advocates, helps them work together, and pools their resources for individuals with diabetes (Diabetes Advocates, 2012). One participant with diabetes is the founder of Diabetes Social Media Advocacy (DSMA) (2012). Participants were not asked to answer the questions, but to provide feedback related to the questions and question choices.

It took participants an average of 25 minutes to complete the survey, ranging from 10 minutes to 40 minutes. The healthcare providers who responded took longer to respond to the questions than those with diabetes. If their feedback is omitted the average time is reduced to 21 minutes. Those under the age of 50 answered the questions in 18.75 minutes while those over the age of

50 spent an average of 33.3 minutes on the survey. Time to complete the survey may have been lengthened given the request to provide feedback.

Participants had concerns regarding the wording of some of the questions on the SF-12, ISCS, and TIS instruments. The SF-12v2 has been reported to have better wording and improved readability over the SF-12 (Maruish & Turner-Bowker, 2009) and will be used in this study. The ISCS and TIS original questions, with the noted revisions, will be maintained for this study.

There were several suggestions related to other questions in the study. In the demographics section, one respondent suggested adding the option of “retired” to employment status. This was added along with the option of “disabled.” As it relates to insurance coverage, the suggestion to use “military related overage” in place of Tricare was accepted. “Medicare disability” was also added.

In the health history section, it was recommended to add in options regarding diet and exercise as a diabetes treatment. This was accepted. Further, options regarding insulin pump and continuous glucose monitoring system were also added. The suggestion to clarify “medical” practice in the health history was accepted. One respondent suggested that seeing a healthcare provider every 3 months was not an option. The word “quarterly” was changed to read “every 3 months” to provide better clarity. There was a suggestion to include “none of the above” when answering questions related to diabetes complications; this was added. One respondent suggested that some individuals may not know that they have latent autoimmune diabetes of adulthood (LADA), and instead, would

answer type 1 diabetes. Given the presence of LADA information on TuDiabetes, and the choice to select whether or not you have LADA when first signing up to be a member of TuDiabetes, the original question will be maintained. If there are few individuals who identify their type of diabetes as LADA, LADA and type 1 diabetes will be collapsed into one category.

The suggestion to add in a question about whether or not your doctor supports the use of your online communities for diabetes was considered, reworded, and added in the Medicine 2.0 application section. One respondent suggested adding questions regarding the relationship a DOC user has with his or her healthcare provider. It was decided that this question would not be addressed in this study. The final questionnaire has 92 questions.